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ABSTRACT

This first volume of the 1981 Report of the Select Panel for the Promotion of Child Health presents the panel's major findings and recommendations in several areas of maternal and child health. Section I, the Introduction, addresses five major concerns related to health care that were identified by the panel. These concerns were (1) that programs to prevent disease and promote health are neither available nor adequately used even when available; (2) that sharp disparities persist in both health status and use of health services according to family income, ethnic background, parental education, and geographic location; (3) that the current health care system insufficiently recognizes or supports the role of the family as the primary source of health care for children; (4) that the organizational, administrative, financial, and professional training aspects of today's health care system have not been adapted to cope with current family health problems; and (5) that public health programs are not working effectively in relation to one another. Sections II through V discuss in detail these concerns and focus in particular on how they can most effectively be dealt with in the 1980s and beyond. (Author/RH)

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BETTER HEALTH FOR OUR CHILDREN: A NATIONAL STRATEGY

U S DEPARTMENT OF HEALTH,
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The Report Of The Select Panel For The Promotion Of Child Health

To The United
States Congress
And The Secretary
Of Health
And Human Services

1981

Volume I
Major Findings And
Recommendations

PS 012109

THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service
Office of the Assistant Secretary for Health
and Surgeon General
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DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF THE SECRETARY

SELECT PANEL FOR THE PROMOTION
OF CHILD HEALTH
1832 M STREET, N.W. — RM. 711
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December 2, 1980

Honorable Patricia R. Harris
Secretary
Department of Health and Human Services

Honorable Edward M. Kennedy
Chairman, Subcommittee on Health and Scientific Research
Senate Committee on Labor and Human Resources

Honorable Henry A. Waxman
Chairman, Subcommittee on Health and the Environment
House Committee on Interstate and Foreign Commerce

Dear Secretary Harris, Senator Kennedy, and Congressman Waxman:

I am proud to transmit to you the report of the Select Panel for the Promotion of Child Health, in accordance with Public Law 95-626 which created the Panel.

The 17 members of the Panel and our staff have devoted an extraordinary amount of time, energy, and--we hope--wisdom to our task. Our commitment has reflected how seriously we have all come to take the opportunity offered us by the breadth of the mandate Congress assigned to us. The chance to design the foundations of a national effort to improve the health of our children has infused our work with excitement and zest. It has also permitted us to mobilize the contributions of hundreds of individuals and organizations throughout the country, engaged in large ways and small in understanding and serving the health needs of this country's children and families. The Panel, and the Nation, are profoundly in their debt.

We were impressed with the richness and diversity of available talent, competence and commitment, reflected in the accomplishments of a great variety of public programs and private efforts in communities throughout the country. We also became starkly aware of the extent of the unsolved problems that remain.

Our recommendations reflect a hardheaded analysis of serious unmet needs in child and maternal health, a recognition of past successes and future opportunities for effectively meeting these needs, careful consideration of the weaknesses and strengths of current Federal programs and policies, and a sober and pragmatic assessment of the capacity of our institutions to provide parents, professionals, and others working to improve child health with the scientific, financial, and organizational support they need.

Volume I of our report presents our major findings and recommendations.

Volume II contains specific recommendations for improving five major Federal programs with significant impact on child health:

-- Title V of the Social Security Act
-- The Special Supplemental Food Program for Women, Infants and Children
-- P.L. 94-142: The Education for All Handicapped Children Act
-- Medicaid and EPSDT
-- Community Mental Health Centers and Services Systems

Volume III consists of what we believe to be the most comprehensive compilation of data on child health in the U.S. yet to be published.

We also submit a collection of background papers, listed at the end of Volume I, which were prepared for the Panel, and which we believe will be extremely useful to those who wish to become familiar in greater depth with selected aspects of the issues we have analyzed.

Some of our recommendations should be acted on immediately. Others are designed to be considered and implemented over a period of years. All of our recommendations are practical, and as specific and concrete as we have been able to make them.

The goals we set out encompass an extremely broad sweep of issues. In accordance with our congressional mandate we have addressed and analyzed issues and policies pertaining to the physical environment, health behavior, health services organization and financing, and health research. We did not try to go beyond these, although we are fully aware that other aspects of the social environment exercise a powerful influence on health. It is true that if we could eliminate poverty and racism in this country, if high quality preschool programs and community supports for families were more available, if teachers and schools were more effective, if we had full employment and every young person could look forward to productive work, our health indicators would improve significantly. Nevertheless, we have not focused on these issues, both because they are outside the Panel's mandate, and because we wish to help direct public attention to the extensive opportunities to improve child health by improving health policies and programs.

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The Panel has asked me to call your attention to an additional problem we faced in defining our mandate. As you know, the legislation that established the Panel asked us to look at the health of "children and expectant mothers." Child health is obviously inseparable from maternal health. The health of the mother during pregnancy is unquestionably a major determinant of child health. But as we looked beyond purely physiological factors in child health, we found that our concerns must include fathers as well as mothers, both in relation to their role in the decision to conceive a child, and to their continuing role in providing nurturance, support, protection, and guidance to their children as they grow. Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on a child's health. We wish to be clear that our use of the term "maternal and child health," when we describe and analyze both needs and interventions, is in no way inconsistent with our conviction that fathers as well as mothers are central to raising healthy children.

We are grateful for the opportunity you have given us to engage in this work, and thank you for the help and support we have received from you and your associates in the course of our deliberations. We trust that the value of our efforts will prove to have justified the investment that the American public has made in the creation of this report.

I am sure you share with us the conviction that public policy, no matter how well conceived and carried out, can contribute only modestly to the vigor, grace, and joy we wish to see in our children's lives. But as our report makes clear, public policy and programs can mean the crucial difference, especially in the lives of the most vulnerable of our children.

We hope most profoundly that this report will contribute to shaping public policy in ways that will help all American families and communities to protect and promote the health of all of our nation's children.

Respectfully and sincerely yours,

Lisbeth B. Schorr

Lisbeth Bamberger Schorr
Chairperson

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†The Panel members who are representatives of the Department of Health and Human Services wish to commend the Panel as a whole for its thorough information gathering and careful analysis of child health problems. They believe the Panel's report is an extremely useful document. However, the specific programmatic and budget recommendations contained in the report have not yet been formally considered by the Department or by the Executive Office of the President. Thus, participation by Department representatives in the Panel's activities cannot be construed as an Administration endorsement of the recommendations.

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Volume I
Major Findings And Recommendations

Children are one-third of our population and all of our future

SUMMARY

It is a biological fact that human infants and children depend upon others to an extent not found in any other species. In tacit recognition of this fact, all human societies, ancient and modern, have developed elaborate systems of shared family and community responsibility for the young. The makeup of such systems and the precise division of duties within them have varied from one culture to another and from one generation to the next. But the central theme of shared responsibility for the young endures.

In the United States today, our system of shared responsibility has contributed much to ensuring the healthy growth of our children. But despite great achievements, we are still falling short of doing what we believe most Americans want to see done to promote the health of all our children. In recognition of this fact, the Congress created a Select Panel for the Promotion of Child Health to assess the status of maternal and child health and to develop, for the first time, "a comprehensive plan to promote the health of children and pregnant women in the United States."

The 17 private citizens and public officials who undertook this task carefully scrutinized existing maternal and child health data, knowledge, and experience. We found widespread consensus about the interventions likely to be effective, about the programs that work well and the obstacles that keep them from working better, about ways to get the most out of the money we are already spending, and about improvements that could be achieved for relatively little more. We have also found that a large proportion of the most burdensome child health problems can be prevented or ameliorated at reasonable and predictable costs through the application of knowledge already at hand. The Panel was struck by the contrast between how much we know about promoting the health of pregnant women and children and how little is actually reaching some of the most vulnerable among them. Similarly, we were impressed by the number of highly successful efforts currently underway throughout the country, but discouraged that they have not been systematically built upon and expanded.

Even though we discovered much agreement on what needs to be done, we found the task of developing specific proposals to improve maternal and child health even more formidable than we originally anticipated. It soon became evident that our very mandate was bucking widespread feelings of alienation from Government, and a rising tide of cynicism and hostility toward all social programs.

We believe that it is possible to take account of these currents in our political climate without becoming immobilized by them. We recognized early in our work that we must be cost-conscious as well as compassionate; incremental but with a clear vision of the long-term goals toward which we aim. We have tried, as Congress asked of us, to be comprehensive, but without being unrealistic. We have made some sweeping but practical proposals. They reflect the broad consensus in the land that even the best public programs and policies can be made to function better when they are more rationally and coherently related to one another.

Perhaps most important in terms of providing a basis for action over the next decade, our proposals are justified by both a human concern for the young and the self-interest of adults. Our recommendations to promote maternal and child health are based on our deep belief—shared, we are convinced, by most Americans—that children matter for themselves, that childhood has its own intrinsic value, and that society has an obligation to enhance the lives of children today, quite apart from whether we can prove later benefits in adulthood.

We do not rest our case solely upon such convictions, however. What we offer is also a prospectus for a sound investment in America's future, in economic as well as social terms. Healthy children represent a major economic asset. As today's children grow to adulthood, they will have to perform increasingly complex tasks, in an age of constant technological change, in order to protect our natural environment, maintain our standard of living, keep our economy competitive with other nations, preserve our defense capabilities, and maintain our humanitarian values. We will tomorrow be dependent upon the very children who today are dependent upon us. Each and every one of them—male and female, rich and poor, black, brown, and white—is both a precious individual and a valuable national resource. Improving the health of today's children not only enhances the quality of their lives immediately, it also expands their potential for significant contributions to the Nation as adults.

We call upon all Americans—public officials and private citizens, parents and professionals, leaders at the local, State, and Federal level—to join in concerted efforts to make certain that policies and programs in the 1980's, in both the public and private sectors, reflect a commitment that does justice to the needs of all of the Nation's children.

CHAPTER SYNOPSIS

Section I—Introduction

Chapter 1: Major Concerns

In the course of our work, five overriding concerns emerged. It is to these concerns that we have addressed our analysis and recommendations:

(1) Many forms of disease prevention and health promotion are demonstrably effective, especially for children and pregnant women, but still are neither widely available nor adequately used even when available.

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(2) The health status of American children has improved dramatically over the past two decades, but not all groups have shared equally in the progress. Sharp disparities persist in both health status and the use of health services according to family income, ethnic background, parental education, and geographic location.

(3) The profile of child health needs has changed significantly over the course of this century, partly as a result of success in combating infectious disease, partly because new problems have emerged. But the organizational, administrative, financial, and professional training aspects of our health care system today have not been adapted to cope with current health problems, which have intertwined psychological, environmental, social, and behavioral components.

(4) While the family is and will remain the primary source of health care for children, the current health care system insufficiently recognizes or supports this role. Nor has the system acknowledged or adequately responded to the health implications of the changing composition and circumstances of the American family.

(5) The Nation's increased investment in maternal and child health over the past two decades has spawned many new programs, but they are not working effectively in relation to one another. Public programs have made a significant contribution to improving the health of the Nation's mothers and children, but there remain gaps in and between services; fragmentation and duplication in both programs and services; and conflicts among various levels of government and among a variety of programs.

Section II—Health Protection and Promotion

Many of the strongest influences on child health lie beyond the reach of personal health services. These include the social environment, the physical environment, nutrition, and health-related behavior.

Factors in the social environment such as family income, parental education, opportunities for productive work, minority status, child care arrangements, and the availability of community supports for adolescents and parents of young children all exert a powerful influence on health. We recognize the significance of these influences, but offer no extensive recommendations in this area because it lies beyond the scope of our mandate.

Chapter 2: Reducing Environmental Risks

Hazards in our physical environment can profoundly affect the health of our children both before and after they are born. Our review of the evidence on environmental hazards to mothers and children suggests there are four risks which deserve special attention in the coming decade: accidents of all kinds, with emphasis on motor vehicle accidents and those in the home; chemical and radiation risks, including those posed by toxic

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wastes, pesticides, lead and other pollutants; hazards from drugs and foods, with particular focus on substances presenting special risks during pregnancy; and problems caused by inadequate or unhealthful water supplies, with attention to the need for wider fluoridation, potable water in all homes, and adequate sanitation. These four types of risk include old problems which could be prevented through the application of knowledge already in hand, and new or newly discovered problems, which often are complex in causation and less easily understood or addressed.

Accidents, especially motor vehicle accidents, are the leading cause of death and disability among children and adolescents. The United States is second only to Canada among ten Western industrialized nations in its rate of accidental deaths among children. The Panel believes this state of affairs is unacceptable, and can be changed in a Nation as resourceful as ours. A major new national accident prevention strategy should be initiated, with strong participation by private industry, citizen groups, the media, and Government. This strategy should take advantage of both private initiatives and public policy instruments, including technical innovations, regulatory actions, and new approaches to education of children and parents.

The evidence suggests that many kinds of injuries and health problems can be more economically and effectively reduced by changing the environments in which people live, work and play, than by trying to change behavior directly. Thus, for example, safer automobile construction and better passive restraint systems in automobiles may be more effective than increased expenditure on driver education.

Among the most worrisome, pervasive, and complex environmental health hazards are the numerous chemicals and sources of radiation to which Americans are exposed in the home, at work, and in the neighborhood. Toxic chemicals and radiation pose special risks for pregnant women and for children because of the unique susceptibilities early in the life cycle and because effects may be cumulative over the lifespan. The Panel believes the Nation should clean up chemical wastes, establish safe exposure levels for insecticides and pesticides, monitor the use of X-rays, and take other necessary actions to protect the health of current and future generations.

One traditional public health objective which requires no new technology or knowledge is the elimination of obvious contaminants and sources of infectious disease from water systems. Most Americans now benefit from safe and healthy water, but three problems remain: many community water supplies are still not fluoridated, some families still lack indoor plumbing, and certain potentially dangerous chemicals are still found in drinking water.

The Panel believes that effective strategies to reduce environmental risks for children and pregnant women must involve all Americans, and not just the Government. Strategies for health protection should not be automatically equated with regulatory action. But if Federal policy is to continue to play an important role in protecting the health of children and pregnant women, various Federal agencies will need to strengthen considerably their coordination with one another over the coming decade.

Chapter 3: Health and Behavior

Health-relevant behavior is an integral part of lifestyle, which starts forming in infancy. It is influenced by a wide variety of factors including the examples set and instruction given by parents, siblings, peers, schools, religious and community groups, and the media. Socialization—the combined effect of all these factors—is far more powerful than any single attempt to teach new behaviors. But we now know a good deal about how education in the family, schools, the media, the workplace, and the community can exert a significant positive influence on health habits.

A mother's influence on the health of her child begins even before birth, when a number of maternal habits such as smoking, drinking, and drug use can affect the outcome of pregnancy. The Panel believes that prenatal counseling and anticipatory guidance for parents, including preparation for childbirth and education for parenting, should be more widely available from health care providers, private voluntary organizations, and community agencies. Similarly, guidance and support in the period immediately after birth and in the first year of life can help a family cope with issues of infant feeding, how to manage a difficult baby, how to recognize illness, and how to provide a safe and stimulating environment for an infant. The perinatal period also is an opportune time to link women and their families with other services and supports to ensure continuity in the availability of primary care.

The rapid increase in numbers of preschoolers attending early education and day care programs offers a new opportunity for health-related education. Eating habits, dental health practices, and other health behaviors have their roots in early childhood, and the Panel urges that preschools and programs such as Head Start be used as sites for health education and parent counseling as well as early identification of health problems.

Television exerts a powerful influence on formation of behavior from a very early age. The Nation must improve the quality of programming directed at children, particularly with regard to both implicit and explicit health messages; we must also preserve our capacity for regulatory action aimed at mitigating any negative health consequences of television programming and advertising targeted toward children. In addition, parents, policymakers, and community groups should encourage alternatives to excessive television viewing among children. Inordinate time spent watching television diminishes the opportunity for more active ways of learning about life.

Many school health education programs at present are neither sufficiently comprehensive nor sufficiently attuned to the influence of peer culture and other important determinants of youthful behavior to be truly effective in promoting good health habits. The content of school health education should remain a matter for local determination involving active parental participation, but should include sound information and guidance on such topics as eating habits and nutrition, exercise, smoking, alcohol and drug use, driving safety, human sexuality, family development, coping and stress management, and environmental conditions

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affecting health. Physical education programs in particular are an area of vast unrealized potential. These should place new emphasis on lifetime fitness and health maintenance skills as well as competitive team sports.

Because so many forms of behavior with lifetime health consequences are formed or first tried in adolescence, health education activities are especially important for youngsters 10 to 18 years old. Although most adolescents are physically healthy, problems ranging from accidents to substance abuse and unwanted pregnancy can result from immature judgment combined with uncertain self-esteem and strong peer pressure. Adolescents need more information about the effects of their lifestyle on their present and future health, but such information must be presented in ways which are likely to be taken seriously by them. This suggests a special responsibility for those most likely to be heeded by teenagers, including influential teachers and community leaders, sports figures, and television and radio celebrities.

Chapter 4: Improving Nutrition

The critical role that nutrition plays in health has not been adequately recognized by the health community generally, including those whose principal focus is maternal and child health. We share the developing consensus that nutrition is a major, not marginal, component of efforts to promote health and prevent disease, especially during pregnancy, infancy, childhood, and adolescence when the human organism is growing and developing.

While there are still some who lack adequate food, starvation and gross nutritional deficiency diseases are no longer the major problems they once were. Today's nutrition problems are more likely to involve dietary excesses and imbalances which may in turn be implicated in the development of leading chronic degenerative diseases. Adequate nutrition is especially important for some mothers and children who, by virtue of such factors as socioeconomic and minority status, age or cultural background are at special risk of nutrition-related problems.

The Panel identified four ways to improve the nutritional status of mothers and children:

(1) There must be a new and vigorous commitment in the health system, schools, the media, private industry, and Government to inform and educate families more adequately about health-promoting and risk-reducing diets. The Panel urges the Federal Government to take a major leadership role in developing and disseminating norms for appropriate nutrition. Nutrition-related guidance must take cognizance of our new "nutrition environment," which is characterized by new patterns of eating, a rapidly changing food supply, phenomenal growth in convenience and processed foods, and fast food restaurants.

(2) Nutrition services must be better integrated into health care. Health care providers should specifically address their patients' nutrition-related needs as part of the full range of health services offered, and should link their practices to nutrition services in their communities.

(3) Existing public food programs also must be strengthened and expanded. Over the long run, the Supplemental Food Program for Women, Infants and Children (WIC) should be enlarged to serve all who are eligible by income and nutritional risk; State and local health care systems which provide the base for the WIC program should be expanded accordingly.

(4) Research is needed to develop a better understanding of children's diets, nutrition, and health status; to identify individual and family nutrition-related behaviors that increase children's risks of disease and to develop ways to help families change such behaviors; and to develop greater understanding of the effects of early feeding patterns and nutritional status on long-term development and adult health status.

Section III—The Content, Organization, and Financing of Health Services

The Panel concluded early in its work that any proposals we might make for changes in the organization and financing of health services should grow out of an assessment of what services children and pregnant women actually need, in addition to an analysis of current patterns of service use and the strengths and shortcomings of existing programs. We focused our attention most heavily on primary care, in the belief that it is the area with the most urgent unsolved problems. Similarly, we directed much of our analysis to the way in which health services for mothers and children are organized and financed, believing that such health system components exert a major influence on health status.

Chapter 5: Needed Services

The task of defining "needed services" was a fundamental first step in the Panel's work and served as the basis for many of our subsequent recommendations, particularly those regarding the organization and financing of health services. Because health problems in this group range from the biomedical to the psychosocial, needed services include services such as counseling, anticipatory guidance, and various information and education activities oriented primarily to psychosocial issues, in addition to traditional medical care.

We focus mainly on services that are preventive in nature and are typically delivered through primary care systems. This orientation stems both from the Panel's mandate and from our belief that many of the strategies most likely to decrease overall mortality and morbidity in mothers and children lie in the domain of preventive services and primary care. This emphasis is accompanied by our conviction that the expansion and improvement of secondary and tertiary services to mothers and children who need such care is also critical and requires more adequate resources and improved coordination between primary care and more specialized services.

Chapter 5 presents lists of health and health-related services that should be fully available and accessible to women in the reproductive age span, including pregnant women; infants in the first year of life; preschool and school-aged children; and adolescents.

The process of defining needed services led us to three major findings. First and most important is the conclusion that for three broad classes of services, there is such a clear consensus regarding their effectiveness and their importance to good health that it should no longer be considered acceptable that an individual be denied access to them for any reason:

- Prenatal, delivery, and postnatal care
- Comprehensive health care for children from birth through age 5
- Family planning services

A second category of services which merit special attention includes mental health and related psychosocial services, dental services, genetic services, and services that promote access to care. Although each has unique attributes, they have in common not only their importance to health but also the fact that they are not now adequately available, particularly to some of the groups most in need of them, and that they have not been accorded sufficient prominence in current views of the essential components of maternal and child health care services. By singling them out for specific discussion, the Panel hopes to strengthen the national consensus regarding their value in health promotion.

Third, a new mechanism is needed to serve a variety of functions aimed at improving the content, quality, and availability of health services for mothers and children. One reason many services we have identified as needed are unavailable or underutilized is that they are not covered by public and private third-party payment plans, in part because of the nature of the services themselves. They tend to be difficult to define precisely, and—in greater measure than is true for medical services—their effectiveness appears closely related to the circumstances under which they are provided, by whom, and in relation to what other services. To help provide information on such issues, we recommend that a Board on Health Services Standards be created, or existing institutions strengthened and consolidated, to perform the following functions:

- Review and define the health services that should be available to mothers and children in light of new knowledge and changing health problems.
- Provide guidance to third-party payers and purchasers of health insurance regarding the effectiveness and appropriate use of a given service or sets of services, and the circumstances under which such services should be provided and financed.
- Provide information to third-party payers regarding the likely effects of their payment policies and practices on the availability of needed services, professional personnel, facilities, and other health resources.

So that work along these lines can proceed promptly, we recommend that the Secretary of Health and Human Services convene an ad hoc group to propose the precise nature, composition, and authority of the

Board within the broad guidelines we propose, and that the Congress act rapidly to establish the Board or a similar mechanism to perform these important functions.

Chapter 6: Improving the Organization of Health Services

Primary care for children and pregnant women is currently provided under a wide variety of arrangements, which range from private physicians' offices to the public schools, from health department and hospital clinics to community health centers and health maintenance organizations (HMO's).

American communities vary so widely in their needs and resources, and prize so highly the diversity of their own ways of solving problems, that it is neither feasible nor wise to attempt to move the Nation toward one standard way of delivering health services to mothers and children. However, we have identified specific organizational attributes which should be incorporated into all provider arrangements. The effective organization and structuring of services is especially important for families with handicapped, chronically ill, or severely ill children; for pregnant women who for social or medical reasons are at high risk; and for low-income families, who have greater needs for health and related services and fewer resources to negotiate their way around a complicated maze of fragmented health services. Since these categories of families include perhaps one-fifth of all children and pregnant women at any one time, and one-fourth to one-third over a period of years, the need for more highly organized primary care is not circumscribed, but spread widely throughout the population.

The attributes that we have identified as important components of effective primary care provider arrangements are:

- Comprehensive services
- Accessibility
- Capacity for outreach
- Coordination of services
- Continuity of care
- Appropriate personnel arrangements
- Accountability
- Consumer participation
- Partnership with parents

We have analyzed a number of existing provider arrangements with these attributes in mind, and have made proposals for strengthening them.

We believe that, over the long term, primary care physicians should be encouraged to join in practice with other physicians and with other health professionals. Dentists, too, should be encouraged to join in practice with other dental professionals. Simultaneously, new efforts must be made to develop better links between providers in office-based practice and other sources of care, services, and support in the community.

Hospitals that provide a substantial amount of outpatient care to children and pregnant women must make fundamental changes in their

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organizational arrangements by establishing primary care centers, hospital-based group practice, and better linkage with other sources of care in the community. None of this can be accomplished without changes in the financing of hospital outpatient services, and we recommend a number of specific changes toward that end.

Publicly financed comprehensive care settings (including community health centers, migrant health centers, children and youth projects, maternity and infant care projects, some health department programs, and rural primary care centers) have been highly effective in providing previously unreached populations with needed health services, with subsequent decreases in hospitalization rates, infant mortality rates, and the incidence of preventable diseases in the areas served. They remain a model for the delivery of high-quality care in the Nation's areas of provider scarcity and high health needs.

We believe these programs, along with the deployment of National Health Service Corps personnel, are the best instruments for increasing access to and availability of primary care services for children and pregnant women in underserved areas, and that the Congress should increase its grant support to allow existing comprehensive care centers to serve more clients and to permit their expansion to additional sites.

Because HMO's provide cost and quality controls, the opportunity for collaboration among a variety of health workers, and a system of financing which encourages the provision of primary care and preventive services, the Panel urges that all HMO's expand their ability to provide needed services to children and pregnant women, and that Federal authorities take the steps necessary to make it more attractive for HMO's to enroll low-income mothers and children.

Support for primary care units organized and sponsored by qualified local and State health departments will be even more important during the next decade than in the past. In many areas, no other provider is as likely to offer care at moderate expense to the inner city or rural poor and the medically indigent. We therefore recommend that Federal, State, and local authorities support health department efforts to offer comprehensive primary care, rather than individual components of preventive care.

School-based health services should be considered a desirable way of delivering primary health services to school-aged children, and possibly to preschool children, in those communities where it is possible to utilize schools as the *site* for the provision of health services rendered under the auspices of an appropriate health agency, and where parents support and actively collaborate in fashioning and maintaining such arrangements. Nonetheless, there are many school systems where it will not seem wise to locate a comprehensive primary care program in the schools. In such instances, professionally qualified nurses should provide health education, counseling and preventive services, work with parents to link children with other health services, and provide professional nursing supervision for children with chronic illness or handicapping conditions. Similarly, we believe a more extensive commitment of resources aimed at improving health services for children in day care, Head Start, and other preschool programs is essential.

Chapter 7: Delivery Problems of Special Concern

In its review of arrangements for the delivery of needed health services to infants, children, adolescents, and pregnant women, the Panel identified a number of special challenges or opportunities in organizing health services that cut across individual provider arrangements. We believe these should be specifically addressed in the formulation of public policy.

Home Visiting

Renewed interest in home visiting services has developed from a growing recognition that many services are best provided outside of large institutions, that traditional sources of support for many pregnant women and new parents are often no longer available, and that efforts to link persons with the services they require are often essential to obtaining good health care. Federal, State, and local authorities should substantially increase their support for home visiting programs. Such increased support should be of sufficient magnitude to: permit a substantial number of States and communities to use home visits by public health nurses or other qualified personnel as one means of ensuring access to the minimum basic health services for children and pregnant women discussed in chapter 5; enable various health care providers to establish or reestablish home visiting programs as a routine component of maternal and child health care; and allow for the evaluation of a wide range of programs.

Primary Mental Health Care

Many health problems which come to the attention of primary care practitioners are either emotional in origin or have important psychosocial components. Furthermore, a significant portion of what might be termed "primary mental health care" is in reality provided in general health care settings and in schools, day care centers, juvenile detention facilities, and other sites by personnel not specifically trained as mental health professionals. These facts must be better recognized in the organization and financing of services, in the training of health professionals, and in arrangements to provide expert mental health support and consultation to parents, general health care providers, teachers, day care workers, social workers, correctional officers, and others who deal with children and their families daily.

The time is ripe for new and systematic efforts to organize and finance primary care—especially for children and pregnant women—in ways which will encourage adequate attention to psychological, social, and behavioral components of care and which encourage referral, consultation, and ease of communication between mental health professionals and primary care providers, and agencies, institutions, and professionals who deal with children, pregnant women, and parents in trouble.

Categorical Services

In the main, primary health services for mothers and children are provided most effectively in settings that offer a comprehensive array of needed services. But there is persuasive evidence that some services are well provided in settings that are not organized to provide comprehensive care. For example, the Panel recommends that categorical funding for family planning services be expanded to ensure that these services continue to be made available in a variety of settings, and that all persons who wish to make use of family planning services will have access to them.

The potential effectiveness of providing preventive dental services to school-age children through categorical programs has been grossly neglected. Certain basic preventive dental services are so critical to improving the dental health of the Nation that they must be available to all children and in various sites such as public schools, which simplify access and provide substantial economies of scale.

Mass Screening

Screening is useful (a) when performed in the context of individual assessments and continuing care, (b) as a means of detecting a limited number of conditions characterized by simplicity of detection and followup, (c) as a way of linking children to an ongoing source of care, and (d) as a check on the adequacy of care that children are receiving. Developmental assessment is a key component of the health assessment of every child, but developmental assessment of young children is not properly performed as part of a mass screening program, and should be carried out only in the context of a more comprehensive health or educational assessment.

Hospital Care

The operating and staffing policies, environment and design of space, and philosophy of care of all hospitals offering pediatric and obstetrical care should reflect the developmental and psychosocial needs of children and families in health care settings. All hospitals with emergency rooms that treat children should ensure the availability of special pediatric equipment and of medical and nursing staff knowledgeable in the care of critically ill or injured children.

Regionalization

The Panel urges increased support for the regionalization of selected health services for children, newborns, and pregnant women, including further development of regionalized perinatal care networks; genetic services; networks to improve care for serious illness and accidents; backup and referral services for diagnosis and treatment of children with chronic illness, handicaps, or complicated psychosocial problems; and enlarged public and private support of children's hospitals in their role as regional resource centers and providers of specialized care.

Chapter 8: Organizing Services for Special Populations

Four populations of children present special challenges to the effective organization of services: adolescents, chronically impaired children,

children in foster care or other out-of-home placements, and children with serious access problems as a result of linguistic, cultural, or geographic separation from the mainstream of society.

The health care needs of adolescents require increased attention in existing health services systems, and efforts must be made to develop and refine innovative models for organizing services to meet special health needs arising during this important period in the life cycle. Outreach systems should be targeted to the settings where adolescents spend most of their time; counseling should be a major component of adolescent health care; sensitivity to issues of privacy and confidentiality must be reflected in the design of services for this population; and financial barriers to care must be significantly reduced or eliminated.

Certain basic principles should govern the provision of all health services for chronically impaired children—a group including the chronically ill, physically handicapped, mentally retarded, emotionally disturbed and multiply handicapped. Routine care should be provided in the home or as near to normal settings as possible; hospitals should design systems that maximize use of nearby homelike settings, including hospice care where necessary; primary care needs including mental health, dental care and support services for children and families should not be overlooked; and the hidden costs of care for chronically impaired children should be taken into account in private and public financing of care. Clearer guidelines and specifications are needed in a number of public programs directed at these children. The efforts of maternal and child health authorities in this regard should complement school-based efforts under P.L. 94-142, the Education for All Handicapped Children Act.

Juveniles in confinement and in foster care are often overlooked by the health care system. Detention and correctional facilities have an obligation to meet the health and mental health needs of juvenile offenders, and offenders should not be placed in facilities which lack services to meet their needs. The Panel also recommends that required care plans for children in foster care include thorough periodic assessments, and statements of the children's health needs, the health services being provided, and the agencies or individuals responsible for providing such services.

Migrants and farm workers often have inadequate access to publicly financed health and social service programs, which typically depend on stable residency as a criterion for eligibility. The Migrant Student Record Transfer System, a computerized system enabling education authorities to track migrant children from school to school, should be used to link migrant health service programs so that selected health information can move with the child as families change location. In addition, State health plans should contain explicit provisions for meeting migrant health care needs.

Native American children also have special health care needs. Increased numbers of Native Americans should be helped to enter the health professions; more team care should be available; alcohol abuse and other behavioral problems should be effectively addressed; water and sanitation services should be expanded; and primary care for urban Indians should be improved.

While refugees, "entrants," and illegal immigrants all share common problems in obtaining health services, they are treated quite differently by law and public policy. For refugee children the main problem is the discontinuity which is built in by the 3-year eligibility limit for benefits under the Refugee Act of 1980. No distinction should be made between refugees and "entrants" in determining eligibility for health care for children and pregnant women. In areas where illegal immigrants represent a significant component of medical indigents, means should be sought by the Congress, the Department of Health and Human Services (DHHS) and the States to provide fiscal relief to hospitals and primary care providers requiring such assistance.

Chapter 9: Financing Health Services

The way in which health services are financed is the single most important determinant of how the health care system operates, what services are available, which professionals provide those services, and who will receive them. Current public and private third-party payment systems provide incentives that result in an allocation of physician time, distribution of physicians by speciality and location, and a manner of providing health services that collectively are unresponsive to a significant part of patient needs, especially those of children and pregnant women, and that unnecessarily drive up health care costs. Further, current financing arrangements leave millions of Americans with no public or private health insurance protection whatsoever, and many millions more with grossly inadequate coverage.

Purchasers of health insurance, public and private third-party payers, and health care providers should take steps to modify and create alternatives to prevailing methods of reimbursing health professionals and institutions, including:

- Revision of payment schedules and methods to reflect the value of counseling and other time-intensive aspects of primary care and to decrease inappropriate incentives for performing technical procedures.
- More widespread use of alternatives to fee-for-service payment methods.
- Methods of reimbursement that offer equal incentives for training health professionals in ambulatory care and inpatient settings.

Third-party payers and purchasers of health insurance need better guidance on which services are in fact needed, who is qualified to provide them and under what circumstances. The Board on Health Services Standards recommended in chapter 5 is designed to provide such guidance, and also to provide information regarding the likely effects of third-party payment policies and practices on the availability of needed services, professional personnel, facilities, and other components of the health care system.

Private Health Insurance

The potential of private health insurance plans for advancing maternal and child health remains to be fulfilled. Toward that end. the Panel recommends that State insurance commissioners review private insurance policies approved for marketing in their States and grant certification to those that meet the health needs of children and pregnant women. In determining which policies merit certification, the States should use criteria advanced by the proposed Board on Health Services Standards.

Medicaid

The Medicaid program has removed economic barriers to needed care for many poor families. However, the adequacy of the program varies greatly among States, and in some instances, restrictive State policies result in tremendous economic hardships and barriers to needed care for millions of families. For example, in 19 States, women who are pregnant for the first time do not qualify for prenatal benefits. Only about two-thirds of all poor children are eligible for Medicaid; and an estimated 7 million children who meet Federal criteria of poverty cannot receive any Medicaid benefits at all. This is because many States do not allow children of two-parent families to participate in Medicaid, because income standards for eligibility are low in some States, and because many who are eligible during part of the year lose eligibilty when family circumstances change.

Many current problems with the program could be ameliorated without changing its basic structure as a Federal-State program focused on the poor. The most important improvements are incorporated in several versions of the Child Health Assurance Program (CHAP) pending before Congress; these improvements should be promptly enacted. Specifically, the Panel recommends immediate action to establish a uniform national income and resources standard and the extension of eligiblity to all children and pregnant women who meet that test, regardless of family status or other conditions; to require coverage of a uniform national package of services; to include all qualified providers; and to provide Federal incentives to the States to expand access to services and encourage continuity of care.

National Health Financing Programs

Even if the improvements we recommend are made in private insurance and Medicaid, some people will remain uncovered by any form of health insurance, public or private, and many parents will still be forced to choose between health care for their children and the purchase of other necessities.

It is the Panel's conviction that the health care needs of children and pregnant women will be best served over the long run by a national health financing program that ensures universal entitlement to health care. If such a plan cannot be put in place relatively soon, the Panel urges enactment of national health insurance for pregnant women and children to 18. If it proves necessary to phase in eligibility even for this population, the Panel recommends starting with a program covering all pregnant women and children through age 5.

Grant Programs

The Panel supports the use of expanded grant programs to:

- Encourage the development of resources in geographic areas where the personnel, facilities, or delivery mechanisms to provide health care services are unavailable, and to finance demonstrations of new and better ways to deliver such services.
- Pay for services that are more appropriately financed through grant programs than through third-party payments, and for those where more information is still needed regarding the most effective methods of payment.
- Pay for comprehensive services for persons such as handicapped children who have health care needs best met through special systems or programs.
- Pay for health services for those persons lacking other sources of payment, such as migrant workers, poor individuals not eligible for Medicaid, and illegal immigrants.

Section IV—Governmental Relationships

The Panel concluded that the interrelationship of local, State, and Federal Government in the area of maternal and child health needs reordering and simplification. Suggested changes pertain not only to agencies that provide or support services directly, but also to those that perform broader functions such as planning, monitoring, and advocacy.

Chapter 10: Structuring the System

The major health and health care objectives the Panel has identified can be attained without creating major new public programs. But it is essential to enhance the complementarity of existing programs, clarify responsibilities for those making policy and administering programs, and achieve improved coordination and program management.

The Panel believes that the current disarray of programs and policies is sufficient to merit a major modification in the Nation's policies and programs for improving the health of mothers and children—equal in significance to the creation of the Children's Bureau in 1912 or the passage of the Title V legislation in 1935. The agenda this time must be to simplify program oversight and management while ensuring the achievement of specific, socially agreed-upon objectives. We propose that various steps be taken to establish more coherent State and Federal administrative structures, to redefine the appropriate relationship between State and Federal authorities responsible for relevant programs, and to improve local service coordination.

Every State should work toward placing authority over all relevant funding streams in an appropriate division of the State health unit, and a strong unification of effort should be promoted around all aspects of care for children and pregnant women, including handicapped children.

While it is difficult to increase both State autonomy and Federal accountability simultaneously in working toward national objectives, several steps can be taken that will serve both purposes. These include Federal accountability mechanisms that stress the Federal role in establishing broad performance objectives and standards and the State role in selecting methods for attainment of these; joint applications and reporting forms for all Federal programs related to the health of children and pregnant women; a new set of coordination criteria to be met by all new or continuing legislation and program regulations; and interagency agreements to identify areas of responsibility, define specific steps to be taken, and assign realistic time frames for the attainment of goals.

Title V continues to be an essential element for providing health care services and for increasing the coordination of all State and Federal programs relevant to the health of children and pregnant women. We recommend that Title V be revised and expanded, according to the specifications detailed in volume II of the report, to provide the necessary leadership and policy focus.

It is especially at the local level that the efforts of service providers must be simplified and unified in order to provide effective services. At least two types of local initiative have proven successful: the establishment of a single point of service administration and budget control, and the development of improved methods of case management and case advocacy. Each locality should designate a lead agency or publicly appointed body to assess whether the existing network of private and public health care arrangements is sufficient to meet the health care needs of local children and pregnant women, and to recommend changes as needed.

We also urge Federal, State, and local authorities to take a number of steps to better harness existing policy functions applying to all public health programs. These functions include planning, quality assurance, development of information systems, research and demonstrations, technical assistance-consultation, and advocacy.

Chapter 11: Federal Administrative Arrangements

The new national commitment to protect and promote the health of mothers and children which this report advocates can be best advanced at the Federal level through the creation of a Maternal and Child Health Administration (MCHA) within the Public Health Service, to be made up of the existing Office of Maternal and Child Health, the Adolescent Health and Pregnancy Prevention Program authorized by P.L. 95–626, family planning services supported by Title X of the Public Health Services Act, and possibly other programs at some future time.

Maternal and Child Health Administration functions should include (a) operation of these programs; (b) authority to review and comment on major policy issuances, including proposed budgets and legislation, developed by other agencies within DHHS that conduct activities directly related to maternal and child health with a view toward achieving better coordination of programs; (c) assistance to the States on maternal and child health-related topics to help ensure that all mothers and children within their jurisdictions have access to needed services; (d) responsibility for setting national standards by which to assess the adequacy of the

States' progress in ensuring the availability of the minimum set of basic essential services; (e) coordinating the maternal and child health programs of DHHS with related programs in other departments, such as the WIC program of the Department of Agriculture, and the Education for All Handicapped Children activities of the Department of Education; and (f) research and advocacy. The primary value of the MCHA, in the Panel's view, is that it would be an organizational entity of sufficient stature and prestige to mobilize and coordinate programs and sources of funds in many separate agencies in the service of improved maternal and child health.

The Panel decided against recommending that the EPSDT program be moved from the Health Care Financing Administration (HCFA) into the new MCHA. We concluded that its removal from the rest of Medicaid would create delays and disruptions in providing services. More importantly, its relationship to other maternal and child health programs represents a small part of a much larger issue—the relationship of all Public Health Service (PHS) programs to all programs administered by HCFA. A number of steps should be taken to link the service orientation of PHS with the financing and management capacity of HCFA. The establishment of the proposed Board on Health Services Standards could be expected to supplement HCFA's existing expertise in management and cost-containment and thus enable it to perform a broader mission including health promotion and disease prevention. We recommend that the Secretary of DHHS give urgent consideration to other possible steps in this direction, such as making both PHS and HCFA responsible to a new Under Secretary for Health.

The Panel also proposes the creation of a National Commission on Maternal and Child Health, appointed by the Secretary of DHHS to report every 3 years on the health status and unmet service needs of mothers and children; to recommend policy changes in Federal maternal and child health programs, especially to improve their effectiveness and to enhance coordination among programs; and to serve as an advocate, particularly in Congress, for the health needs of mothers and children.

We also recommend joint oversight hearings by the appropriate committees of House and Senate to increase the coordination of maternal and child health programs that fall within the responsibilities of different committees.

Section V—Manpower and Research

Many of the Panel's recommendations suggest new roles and relationships among the health professionals who provide care to children and pregnant women, and underscore the importance of continued and expanded research.

Chapter 12: Health Professionals

Many of the views and recommendations presented in this report contain major policy implications regarding the training and deployment of professionals in maternal and child health. These include:

- The changing profile of primary care needed by mothers and children, with its emphasis on health promotion and disease prevention activities, requires new components in the training of all primary care providers.

- Meeting the health needs of pregnant women, children, and adolescents will increasingly require a team approach to the delivery of primary care.
- The anticipated increase in the overall supply of primary health care providers in the coming decade makes possible, but does not by itself ensure, better access to health care for those most in need. Improved distribution of services will depend, among other things, on alterations in the deployment of National Health Service Corps personnel and on creative use of providers with different levels of training and expertise.
- Training of maternal and child health personnel involved in program administration and policymaking at the Federal, State, or local level must be modified to equip such professionals with the broad range of skills required for management roles in complex, interrelated service systems and to bridge the worlds of maternal and child health, obstetrics, and pediatrics.

Chapter 13: Research

The Panel emphasizes the importance of research directed toward increasing understanding of the biomedical, behavioral, and environmental determinants of health and disease, and toward the improvement of our health delivery system. A wide array of scientific disciplines, pursued at both the fundamental and the applied levels, must be employed—biomedical, behavioral, and social research, the population-based health sciences, health services research, and related disciplines.

The Panel vigorously supports the pluralism of research orientations and agencies currently supported by the Federal Government, but recognizes such diversity of effort requires broad-scale research planning and coordination. We recommend that the Assistant Secretary for Health undertake periodic and careful review of the activities of Federal agencies supporting health research, and of the relationship of current research priorities to the evolving needs of mothers and children, to minimize the risk of significant gaps developing in the total research effort.

We call attention to several research domains of special importance: epidemiology, prevention, social and behavioral aspects of health, health policy, evaluation research, and research on environmental risks to health. We also recommend strongly that support for fundamental research in the health sciences be sustained and increased as opportunities emerge and resources allow, and that special efforts be made to ensure that support for new or neglected areas of research not be made at the expense of fundamental research.

To support many of the research needs we identify and to improve the content, organization, and financing of health services, a more adequate pool of statistical and survey data is needed on a great variety of maternal and child health issues. We stress simultaneously that massive amounts of data already in hand are inadequately analyzed and reported.

Because a well trained, steady supply of researchers is a cornerstone of any national strategy to prevent disease and promote health, we view the current trend toward erosion of training support with great concern. Also, in order to further stimulate research on the health issues and interventions which are particularly important in primary care and to maternal and child health, the Panel recommends that research training opportunities be increased in ambulatory primary care settings and other settings oriented to health promotion and disease prevention.

PLAN FOR ACTION

The Panel views the spectacular improvements in child health achieved by this nation in the past half century as providing a firm foundation on which to build for the future. We have identified the areas in which major problems persist and further improvements are urgently needed.

To clarify the interrelationship among the many recommendations we make throughout the report, we propose three sets of goals.

(1) The first set of goals is directed at ensuring that all needed health and health-related services are available and accessible to all infants, children, adolescents, and pregnant women:

- First, to ensure universal access to three sets of minimum basic services: prenatal, delivery, and postnatal care; comprehensive care for children through age 5; and family planning services.
- Second, to bring about the more effective operation of governmental activities aimed at improving maternal and child health.
- Third, to improve the organization of health services to reach those population groups with special needs or at special risk, including adolescents, chronically impaired children, children in institutions and foster care, and children in the families of migrant and farm workers, Native Americans, refugees, and illegal immigrants.
- Fourth, to ensure that a family's economic status shall not be a bar to the receipt of needed health services or determine the nature and source of such services, and that the use of such services shall never reduce a family to penury.
- Fifth, to ensure that every child from birth to age 18 and every pregnant woman has access to a source of continuing primary care.
- Sixth, to ensure that every family, child, and pregnant woman has access to all services identified as "needed," not merely those basic minimal services which are part of our first goal. This includes genetic, dental, and mental health services and services to respond to health problems with major social and behavioral components.

(2) The second set of goals we propose addresses the influences on maternal and child health which lie beyond the reach of personal health services:

- First, to encourage all efforts aimed at reducing accidents and risks in the physical environment, and to bring about greater recognition of the particular vulnerability of children and pregnant women to environmental risks.

- Second, to promote greater understanding and acceptance of the critical role of nutrition by private industry, Government, the media, the schools, and community groups as well as by the health system.
- Third, to enlist the schools, the media, industry, and voluntary associations, as well as the health system, in far more vigorous efforts to help individuals adopt and sustain behaviors that enhance health and well being.

(3) The third set of goals we propose is directed at building the knowledge base necessary to further enhance maternal and child health:

- First, to encourage both the public and private sector to pursue a wide range of research spanning not only the biomedical and behavioral sciences, but also the population-based sciences and health service research.
- Second, to recognize that fundamental research remains the cornerstone of many past and future advances in health.
- Third, to ensure that an adequate portion of research support is directed to the special health problems of mothers and children.

It is clear that progress toward achieving these goals will require integrated and coherent action. We recognize the difficulties involved in achieving such action, especially if the necessary steps involve any fundamental change. With an eye to constraints on both available public funds and advocacy energies, we suggest that many changes can be made incrementally without diminishing their effectiveness, as long as there is a clear vision of long-term goals. We urge policymakers and advocates, in adopting such an approach, not to lose sight of the relationships among the parts.

Progress toward these goals will also require considerable attention to detail. For this reason, we devote the second volume of our report to spelling out the implications of our recommendations for immediate action to improve five Federal programs with a major impact on child health: Medicaid and EPSDT, the WIC Supplemental Food Program, Title V (Maternal and Child Health and Crippled Children's Programs) of the Social Security Act, the Education for All Handicapped Children Act (P.L. 94–142), and Community Mental Health Centers and Service Systems. In volume III the Panel also presents a compendium of background data on various aspects of maternal and child health, and in volume IV a series of relevant background papers. Both are intended to provide additional information to assist policymakers and the public to arrive at informed judgments in their efforts to improve child health.

SECTION I

INTRODUCTION

CHAPTER 1

MAJOR CONCERNS

The Select Panel began its work by collecting information from hearings, background papers, interviews, site visits, and expert consultations in an effort to identify and better define major policy issues in maternal and child health (*1*). In this process, we discovered a substantial convergence among diverse groups and individuals throughout the country, including parents, health care professionals, researchers and policymakers, on five overriding problems or concerns. All can be simply stated, although their implications for new policy directions are not always as simple to analyze. All focus on domains of health policy where considerable progress has been made already and the Nation has much to be proud of, but where much still remains to be done:

- Many forms of disease prevention and health promotion are demonstrably effective, especially for children and pregnant women, but are still neither widely available nor widely used when they are available.
- On the average, the health status of American children has improved dramatically over the past two decades, but not all groups have shared equally in the progress. Sharp disparities persist in both health status and the use of health services according to family income, ethnic background, parental education, and geographic location.
- The profile of child health needs has changed significantly over the course of this century, partly as a result of our success in combating infectious disease. As a consequence, our definition, organization, and financing of child health care must be modified to deal effectively with the psychological, social, and behavioral factors that are now major determinants of child health status.
- Whereas the family is and will remain a major influence on child health and the determining factor in how child health services are used, the current health care system seldom recognizes or supports this role. Nor does the system acknowledge or address the health implications of the changing composition and circumstances of the American family.
- The Nation's investment in publicly supported maternal and child health programs has been accompanied over the past two decades by a serious splintering of purpose, governance, and oversight responsibility.

This chapter is devoted to describing these concerns, although they all have been at least partially addressed in numerous other recent papers and reports, which are referenced throughout the text and provide far more detail than can be given here. Subsequent chapters return to these concerns as central themes, and focus on how the Nation can most effectively come to grips with them in the 1980's and beyond. All statistics found in the report, except those referenced at the end of each chapter, can be found in volume III (*2*).

THE CASE FOR EMPHASIS ON PREVENTION

A very strong case can be made that various types of prevention and health promotion work, and that they are not receiving the emphasis they deserve. Renewed national interest and consensus on this point is reflected in the recent Surgeon General's Report, *Healthy People*, which emphasizes that "improvement in health status of our citizens will not be made predominantly through treatment of disease, but rather through its prevention" (*3*). The report points out that preventive measures were in large part responsible for major gains in health status in the past—through improvements in sanitation, housing, nutrition, immunizations, contraception, and other developments. It is generally agreed that many of the remaining health problems will not be resolved by our disease-oriented medical care system, however skilled its personnel and sophisticated its technology, but rather by improving the physical and social environments in which we live, and by changing individual behavior. For the coming decade, the Nation's preventive care agenda must be revised to combat newly emergent or newly understood environmental risks and self-damaging forms of behavior.

The potential benefits of preventive care and health promotion are especially great for mothers and young children. This is partly because positive influences and the avoidance of hazards at the beginning of the life cycle can lead to long-term benefits, and partly because a disproportionate number of the most effective preventive care measures are directed toward pregnancy, birth, and the early years of life. A Canadian task force recently completed a critical review of the effectiveness of numerous preventive care interventions, ranking them according to the quality of evidence to support a recommendation that they be included as part of routine health care for particular age groups (*4*). In the categories of prenatal care and care for infants and children, the task force found ample evidence of effectiveness for various forms of counseling, screening, immunization, testing, and followup. This list and others like it form the basis for the Panel's recommendations regarding needed services, found in chapter 5 of the report.

Some Effective Measures

The main problem, therefore, is not that we lack effective preventive care techniques to assist infants, young children, and pregnant women, but that techniques of known effectiveness still have not been applied widely enough. Data on inadequate availability and use of essential preventive care are to be found in a variety of recent surveys and reports (*5*).

Prenatal Care

Prenatal care is clearly related to positive pregnancy outcome. Many of the risks associated with low birth weight can be identified in a first prenatal visit, and steps can be taken to prevent or correct them. Conversely, late care or no care is associated with low birth weight, increased prematurity rates, increased stillbirths, and increased newborn mortality. A pregnant woman who receives no prenatal care is three times as likely as others to have a low-birth-weight baby (one weighing less than 2,500 grams, or about 5.5 pounds). In 1977, neonatal, post-neonatal, and infant death rates were four times higher for babies born to women who received no prenatal care than for those receiving at least some care (*3, 6*).

Despite the effectiveness of timely prenatal care, fully one-quarter of all pregnant women receive none at all or only belated care. These percentages are significantly higher among poor, black, adolescent, and unmarried women, those in rural areas, and those over 40—the very groups most likely to be at high risk from other causes.

Via the provision of prenatal care, public policy can have a demonstrable effect on pregnancy outcomes among high-risk populations. In New York City, for example, publicly supported Maternity and Infant Care (MIC) projects provide prenatal care for 1 in every 12 births to city residents. Throughout the 15 years the program has been in operation, perinatal mortality rates have been consistently lower for MIC patients than for other patients living in districts where the clinics are located, and also lower than average rates for New York City as a whole (*7*).

Immunizations

Few would disagree that all American children should receive the basic health protection of immunizations. Yet as recently as 1976, one-third of all children under 10 were not properly protected against seven major childhood diseases—measles, mumps, rubella, polio, diphtheria, pertussis, and tetanus. All seven diseases can be fully prevented by immunization; their occurrence can result in severe disability or, in some cases, death.

Since 1977, as a result of the highly effective Childhood Immunization Initiative carried out by the Public Health Service in collaboration with local school districts, State and local health departments, professional medical societies and interested lay groups, this percentage has been cut dramatically. By the time children enter elementary school, only 7 percent now lack polio, diphtheria-pertussis-tetanus, or rubella vaccinations, and fewer still lack measles or mumps vaccinations (*8*). The initiative demonstrates that Federal effort in close cooperation with State and local authorities from various service sectors can exert a strong and positive influence. Although this campaign has yielded a satisfactory outcome in the short term, it must continue so that new cohorts of children entering school in the 1980's will be likewise protected. Recent epidemics of measles and pertussis, and occasional recurrences of diphtheria and polio, remind us that immunizations must be received by each successive generation. Well-organized efforts could improve present immunization levels and rid the Nation altogether of certain infectious diseases, including measles and rubella.

Nutritional Care

Both the course of pregnancy and the condition of the infant at birth are affected by the mother's diet. Subsequent growth and development of young children also depend on adequate and balanced nutrition. Improper nutrition makes it more likely that exposure to infection will result in disease, that resistance to disease will be weakened, and that associated complications of disease will result.

In spite of these generally acknowledged facts, a sizable percentage of all pregnant women exhibit nutritional deficiencies or imbalances, especially iron deficiency. Likewise, over 90 percent of all low-income children are below the recommended dietary intakes for iron, and over 50 percent are lacking in one or more essential vitamins (9). Nutritional problems are especially serious for teenage mothers, who must nourish their own rapid development as well as that of the fetus.

Once again, preventive care programs exist that have shown measurable positive results. The U.S. Department of Agriculture's (USDA) Supplemental Food Program for Women, Infants, and Children (WIC), for example, has demonstrated a positive influence on weight gain during pregnancy and on birth weight through nutrition counseling and food supplements for low-income women. More is said about this and other effective nutrition programs in chapter 4.

Early Childhood Screening for Vision and Hearing Defects

As many as 20 percent of all children in the United States have problems of visual acuity and another 5–7 percent have some form of eye disease. About 10 percent of all children have hearing deficits (*10*). Many vision and hearing problems can be identified in infancy and in the preschool years and some, if not identified and treated at this age, can have lasting detrimental effects. One example is cataracts, whose degenerative effects are far more severe if not treated early. Another is strabismus (misaligned eyes), which if uncorrected usually results in long-term visual deficits, loss of binocularity, or both. A third example is congenital or infection-related deafness, which if untreated in the young child may inhibit cognitive and language development.

Screening and treatment for vision and hearing deficits are well developed aspects of primary medical care, yet a surprisingly high number of defects go undetected or untreated during the preschool and school years, especially among low-income children. Where screening programs have been well implemented by local public health and school authorities, results have often been positive. But national programs and policies that could assist in more thorough screening and followup for low-income children, including the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program under Medicaid, still have far to go before reaching all those who need care (*11*).

Preventive Dental Care

Dental caries and periodontal disease are the two most common oral diseases of children. Both are largely preventable. Dental caries alone affect 95 percent of the population. By age 11, the average American child has three permanent teeth damaged by decay, and among low-income children, the number is significantly higher (*12*).

The most effective method to prevent decay is fluoridation of water supplies or topical fluoride treatment. Yet approximately one-half of all American children live in areas without fluoridated water. Programs in school-based screening and education for oral hygiene have been effective in some areas over the years, but recently have not grown in number. Likewise, the EPSDT program has increased the use of early dental care by Medicaid-eligible children, but only about 20 percent of the target population has been screened, and only 25 percent of those screened have actually been referred for treatment (*13*).

Accident Prevention

Accidents are the leading cause of death and disability among children and adolescents. Motor vehicle accidents alone account for one-fifth of all child deaths each year, and 20 percent of all persons who die in motor vehicles each year are teenagers. Other accidental deaths and injuries most commonly result from drownings and burns, falls, misuse of household products, or various forms of substance abuse.

Certain available forms of prevention are very effective in combating accidents. Especially useful are those that do not require voluntary personal behavior, but instead restructure unsafe aspects of the child's environment. As an example, it is estimated that one-third of all passenger fatalities could be avoided if all cars on the highway were equipped with automatic restraints (*14*). Child-resistant containers have resulted in a sharp decline in the accidental ingestion of prescription drugs by children. Other examples of successful techniques for environmental risk reduction are numerous, but few of them have been instituted or encouraged widely as a matter of public policy (*15*).

Family Planning

The best way to prevent many childhood problems is to make sure children are wanted. Studies have shown that parents who plan and space their children have fewer low-birth-weight babies, as do those who wait to have children until they are beyond their early teens. Private, public, and religious group-sponsored family planning programs have made impressive progress over the past decade in reducing unintended pregnancies, but an estimated 3 million poor and near-poor women, and approximately 2 million sexually active teenagers in all income groups, still are not receiving needed help. Partly as a result, unwanted pregnancy continues to exact a heavy toll in health and emotional costs from individuals and society. In fact, estimates indicate that each year about 300,000 unwanted births occur to married couples; 1 million teenagers become pregnant, many unintentionally; and 450,000 out-of-wedlock births result, half of them to teenagers (*16*).

Although more examples could be cited, there is no reason to belabor the point. Numerous children and pregnant women still do not receive or practice even those forms of prevention and health promotion we know to be highly effective. It is easier to document this problem, however, than to make realistic proposals for solving it. The barriers to appropriate use are both varied and numerous, including financial disincentives to parents and health care providers, disincentives in the organization of health care services, and attitudinal factors. Succeeding sections of this report address the issue of how public policies should be devised or modified to provide stronger incentives for an emphasis on prevention and health promotion.

Costs and Benefits

In an era of high inflation and tight fiscal constraints, all public programs have come under sharp scrutiny as taxpayers demand, and policymakers seek to provide, evidence that programs are providing benefits commensurate with their costs. Therefore, it was not surprising that in the course of collecting information on current maternal and child health programs and policies, the Panel was urged repeatedly by policymakers and child health advocates, as well as skeptics of all stripes, to produce detailed and compelling cost-benefit or cost-effectiveness data. We recognize the political realities underlying this advice, and while we would caution that there are limitations to the usefulness of cost-benefit analyses in the health field, there is ample evidence that services for pregnant women and children constitute an exceedingly cost-effective form of social investment.

Public health professionals have defined three levels of prevention. Primary prevention attempts to avoid the development of a disease by techniques of protection (immunization or environmental control) or promotion (education or nutrition). Secondary prevention is equivalent to early diagnosis and prompt treatment (screening and followup). Tertiary prevention is aimed at reducing the effects of irreversible illness to limit disability and promote rehabilitation (insulin therapy for diabetics, training programs for the mentally retarded). Recent cost-effectiveness data on services of all three types suggest that a substantially greater emphasis on preventive health and mental health interventions is warranted as a form of social investment.

Some of the clearest examples are from the realm of preventive medical and dental care:

- A study by the Centers for Disease Control showed that $180 million spent on a measles vaccination program between 1966 and 1974 saved $1.3 billion in medical care and long-term care by reducing deafness, retardation, and other problems (*17*).

- A 1977 General Accounting Office report to the Congress found the cost of genetic screening at birth plus early treatment for seven common disorders was less than one-eighth the projected cost of caring for an impaired child over a lifetime, even without taking into account the extent to which inflation would drive up long-term costs (*18*).
- Another study examined the costs and benefits of four types of preventive care provided in some early childhood demonstration programs in Texas—vision screening, hearing screening, preventive dental care, and identification of congenital malformations. For each State dollar spent, the study found, more than $8 was saved in long-term care costs and in income loss avoided (*19*).
- The Surgeon General's Report on Health Promotion and Disease Prevention points out that dental caries cost $2 billion per year to treat. A recent analysis reported by the Centers for Disease Control shows that for every additional $100,000 spent on water fluoridation, 500,000 cavities are prevented. If each cavity costs $10 to fill, this suggests a cost-benefit ratio of 1-to-50 in favor of fluoridation (*20*).

Such examples cannot even begin to convey the dramatic qualitative difference preventive care can make in the lives of many children whose prospects, even two decades ago, were bleak indeed. A case in point was provided by a June 2, 1980 article in the *Miami Herald* contrasting the excellent prognosis for an infant whose hypothyroidism was diagnosed in Florida's new screening program for inborn errors of metabolism with the situation of a 40-year-old woman whose hypothyroidism was detected too late to treat. The baby is being successfully treated at home with pills costing pennies apiece; however, the woman has an intelligence quotient (IQ) of less than 35 and is permanently institutionalized at an annual care cost of $24,000.

Many procedures identified with preventive medical care are an important component of preventive mental health as well. Substantial gains have been made in preventive mental health in recent years through genetic counseling, amniocentesis, improved prenatal care and delivery, metabolic screening and followup of infants, immunization, and measures to reduce childhood accidents and poisonings. All of these measures may reduce central nervous system damage, with major long-term costs savings to families and to society.

Preventive Education and Counseling Programs

Whereas evidence of cost-effectiveness is relatively easy to find regarding preventive medical care, it has proven harder until recently to produce such evidence in the broad realm of preventive education or counseling programs designed to enhance parenting skills and the mental health and competency of the young child. This is largely because cost-effectiveness analysis based on the long-term outcomes of such programs poses a major methodological challenge. But recent analyses suggest that attendance at preschools, and efforts in parent education, can themselves

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be a form of prevention, especially for children at risk of health problems, child abuse, or school failure.

One cost-benefit study on a limited cohort of children who attended a compensatory preschool in Ypsilanti, Mich., and were followed thereafter into high school, identified two major health-related benefits. A goodly portion of total costs of the preschool project were offset by later savings because, as compared to a control group, participant children required less special education and no institutional care when they reached elementary and secondary school. Similar findings have now been reported for a much wider array of compensatory preschool programs, and are summarized in a recent GAO report and in various scientific journals (*21*).

A number of other promising preventive approaches aimed at enhancing child development involve the interaction of parents and skilled counselors in the home. Among such programs is Home Start, a variation of the Head Start program which includes education, health, nutrition, and social and psychological services. In Home Start, a home visitor serves as a role model and support for the parents, demonstrating how to help the child develop and learn. Evaluation of the program has shown that, at least in the short term, Home Start children gain significantly over control children on measures of development, and significant positive changes are produced in the way parents interact with their preschoolers. The home visitor model has also proven in demonstration programs to be a cost-effective method of preventing child abuse (*22*). Home visitors need not be highly paid professionals, but rather part-time or full-time community workers.

The Panel is convinced, on the basis of the testimony, research, and background materials it has reviewed, that preventive care should be broadly construed to encompass environmental, medical, and psychosocial interventions of many different kinds during pregnancy and the first years of life. Nearly all forms of prevention are inexpensive, both absolutely and relative to the costs of subsequent care for problems that arise in their absence. To withhold such preventive care in the name of cost containment is penny-wise and pound-foolish at best, leaving aside the question of whether it is morally defensible.

Some Caveats

Although the cost-effectiveness of much preventive care for young children and pregnant women is clear, the Panel would caution that some major limitations do exist in the usefulness of the broad cost-benefit framework and point of view for policy determination, both as a general paradigm and when applied to children's services. Our reservations in large measure echo those presented in a recent report of the Office of Technology Assessment (*23*), but we would argue that special caution is needed in applying cost-benefit analysis to children's programs and policies for several reasons:

- To measure the success of early interventions only in terms of long-term outcomes places a difficult burden of proof on programs and policies for children, and one which health care policy for no other group must sustain. Effects must be very strong to predominate over the impact of years of subsequent life experience. We believe that, as with the elderly or any other age group, it also should be important to show that care improves the quality of children's lives in the short-term. This humanitarian goal is as important as cost-containment or maximum return on social investment.

- Cost-benefit analysis always involves assumptions about whether the status quo is acceptable and whether dollar values can be placed on human life. For example, providing prenatal care for the many women who currently do not receive it in the United States would cost somewhat more than we are now spending but would probably result in a significant reduction in infant mortality, birth defects, and developmental disabilities. How can one base a decision about this form of social investment on the dollar value or opportunity cost of infant deaths and disabilities?
- The case for increased preventive care cannot be argued solely on grounds of cost containment because not all forms of effective prevention will cut costs. Some may, and in fact should, increase them somewhat. Vision screening, for example, is only effective if those identified as needing glasses receive them. In simple dollar terms, it is undeniably cheaper to have a generation of children in which 15 percent cannot see well than to rectify this problem, even if national productivity suffers as a result. Again, it is difficult to design policies or calculate dollar tradeoffs without some prior statement of fundamental social values.
- Choices about which investments to make with limited resources always involve a prior judgment about the scope of permissible cost comparisons. If current national child health expenditure is perceived as the only frame of reference for analysis of alternative investments, some very difficult choices are presented (e.g., is it good to invest in prevention of developmental disabilities even if this means reducing expenditure on some forms of needed acute care?). On the other hand, if total domestic health policy expenditure or total national expenditure is the frame of reference, cost comparisons and issues of opportunity cost broaden considerably (e.g., is it more cost beneficial to invest in early prevention than in various forms of high-technology intensive care? How should investment in preventive health care for mothers and children be compared with various types of national defense expenditure?). We believe that current concerns about cost containment have driven many to consider cost tradeoffs only in the narrowest framework, and would submit that a broader range of cost comparisons is more appropriate.
- In a mixed private and public health care system such as ours, cost-benefit comparisons involving public expenditure for the Nation as a whole may lead to different conclusions from those focused on individual families. For example, almost any kind of sophisticated, high-technology medical care may appear exceed-

ingly costly to finance with tax dollars for all who may need it, but well worth the cost to an individual family whose child may die or suffer permanent impairment without such care.

We state such reservations not because they are new, but because they remind us of the false sense of precision that accompanies many cost-benefit comparisons. We would contrast the fuzziness and limited utility of broad cost-benefit statements with the undeniable usefulness of more narrow analyses comparing the relative cost-effectiveness of two or more specific methods for achieving a desired health outcome. The essence of good national preventive care policy is to be clear and limited in what we promise, to select specific objectives and techniques for achieving them, and to be vigorous in evaluating effectiveness so that money is not wasted.

Adolescents

Most of the discussion to this point has focused on infants, young children, and pregnant women, because many of the best examples of effective preventive care are to be found with these groups. The preventive care needs of adolescents are equally great, however, and continue to present a major challenge to the health care system and other service systems.

Early adolescence is a period when many patterns of health-related behavior with major long-term consequences are first established. It is also a time when individuals experiment with substances and modes of behavior, which, if adopted, can have major adverse consequences for a lifetime. Statistics on contemporary adolescents suggest that better preventive interventions are urgently needed for this group. Increases in the rates of teenage pregnancy, sexually transmissible disease, suicide and homicide, motor vehicle accidents, alcohol and drug abuse are especially distressing.

Increased rates of pregnancy among unmarried adolescents have been a particular source of concern. These have resulted from earlier and more frequent sexual experience and inadequate contraceptive practices. In the period 1971–79, the proportion of girls 15–19 years old who had engaged in premarital intercourse increased from 30 percent to 50 percent. More than one-quarter of sexually active teenaged girls in 1979 had never used contraceptives, and close to two-thirds of this group became pregnant.

The problem in this and other realms of adolescent care is that policymakers have not really known how to address such problems effectively. Preventive measures for adolescents have been less clear-cut than for younger children, for at least the following reasons:

- Few adolescent problems are narrowly medical, and most adolescents at risk are not best served by narrowly problem-focused interventions or techniques involving only medical personnel.
- Many adolescents do not seek out health care providers or personnel in the health care system to help them, except when acutely ill or injured.
- Many of the health "problems" of adolescents are in fact symptoms, and preventive solutions are not necessarily best focused on these symptoms alone (e.g., the availability of a job

training program may do more to reduce adolescent pregnancy in a high-risk area than the existence of a special adolescent health clinic).

- Health programs generally regarded as successful among adolescents are often unique to a particular community and difficult to replicate.
- The controversy around age-of-consent for teenagers, combined with controversy between those advocating children's rights and those advocating parents' rights, leads to ground where policymakers and others fear to tread.
- In some realms, such as sexual behavior, there persists a major political ambivalence about implementing even the least controversial preventive measures (better education about human sexuality and more widely available family planning services). This ambivalence persists among policymakers even though survey data indicate most parents favor more open discussion of sexuality and other matters central to the healthy development of teenagers (*24*).

As a result, national health policy toward older children and adolescents has been a nonpolicy characterized by categorical programs fashioned to address limited health problems. The topic of preventive care for adolescents is raised in various chapters of this report, with the general view that the Nation still does not know how best to meet the preventive care needs of this age group and needs more research, demonstrations and analytic attention to the matter in the immediate future. The tremendous importance of adolescent health care is not questioned.

Financial and Organizational Barriers

Despite a growing recognition of the importance of health promotion and disease prevention, many financial and organizational barriers remain that limit the provision of such services. Foremost is the fact that preventive services are generally not covered by either private or public insurance. Insurance, by its very definition, is designed to spread widely the risk of incurring costs due to illness or injury. The concept of preventive care does not even fall within such a traditional definition.

In the absence of third-party payment, preventive care is often simply not provided—either because consumers cannot or will not pay for it, or because unreimbursed providers cannot or will not offer it. Present incentives drive many providers to offer the most expensive and least prevention-oriented types of care, which are particularly inappropriate for children and pregnant women. The result is that only a tiny percentage of our total national health expenditures currently goes to some form of health promotion and disease prevention, despite outlays of $245 billion in 1979 that are expected to total some $758 billion in another 10 years unless changes are made (*25*).

Organizational barriers also limit the availability of preventive care. Physicians in solo practice or with only one partner often find it difficult to take the time to establish linkages with other service providers such as schools, public health authorities, and social workers who can provide valuable preventive services, some of which may not be directly defined as "health care." Few health care settings, no matter how organized or staffed, have an outreach capacity—which may be important for reaching children and pregnant women most in need of preventive care.

There is a new receptivity to health protection and promotion among many practicing health professionals and medical educators, but whether this is translated into new practice patterns will depend in significant measure on the creation of new financial and organizational structures. New approaches to prevention and counseling have gained impetus from the growing realization among physicians that exclusive focus on physical medical concerns may not be the best way to spend a routine child health visit. Indeed, the basic concept of child health supervision is in transition (*26*). Because the health needs of young and dependent children involve the family as well as the individual, effective preventive care for this age group must be broadly construed to encompass not only the particular intervention or procedure itself but also the necessary education and social support for the family to ensure its effectiveness.

Effective prevention is often a matter of how services are organized, as well as whether an effective technique is available. As one example, a recent comparison of PKU screening efforts in the United States, the United Kingdom, and Ireland concluded that, despite identical clinical testing techniques in the three countries, diagnosis is more likely to be missed in the United States, and treatment delayed, because of inadequate coordination between in-hospital and out-of-hospital health care, and inadequate followup of young infants in the community (*27*).

Preventive efforts can be greatly enhanced by a clear distribution of responsibility among health care providers, the schools, social service providers, public health authorities, environmental protection agencies, and others. Many truly effective initiatives involve close collaboration among these sectors. It is known, for instance, that among the most positive results of recent social policy is the improvement of pregnancy outcomes from community-based programs that include social welfare and school-based as well as medical components (*28*). This type of joint effort is greatly to be encouraged, although at present most communities do not provide sufficient opportunities for it.

Limits of Prevention

Even as we urge modification of the health and social service systems to enhance and expand health promotion and disease prevention services, the Panel is mindful of the limits to what can be accomplished through such an approach. Many of the factors that endanger health—such as poverty, racism, unemployment, criminal violence, poor education—lie beyond the reach of the health system and its preventive care measures, even when broadly construed. Moreover, no matter how much we invest in prevention activities, there will still be diseases and medical problems requiring the best of curative medicine.

The fact that a preventive technique is feasible does not always mean that it is desirable to apply. For example, testing preschoolers for developmental lags and school-readiness may yield useful results in the hands of a skilled clinician, but is potentially dangerous if screening outcomes are used by public authorities to classify or track children. In general, screening for so-called "high-prevalence/low severity" conditions deserves scrutiny, especially if the assessment technique is insensitive or of dubious validity, or if effective followup does not seem likely.

Likewise, even if a particular form of prevention is both feasible and desirable, it may only be worth performing for certain subpopulations or in certain geographic areas. Many forms of prevention can be rendered far more effective, especially in a time of scarce resources, if they are targeted to those groups most apt to need them. Targeting is already reflected in various Federal efforts to vaccinate, reduce infant mortality, and achieve other specific objectives. Such efforts would be further sharpened by better prevention-oriented epidemiology in every State designed to tell policymakers in some detail where, for example, to place resources to improve perinatal care or what measures, aimed at which subpopulations of children, might most reduce childhood accidents. Policy-relevant epidemiology of this sort remains rudimentary in most jurisdictions and does not yet permit refined targeting strategies.

Finally, it cannot be denied that many of the most important decisions to be made regarding prevention are political, not medical, in nature. One might argue quite persuasively that the most effective way to improve the health of the American people both dramatically and rapidly would be to prohibit the possession and use of tobacco products, alcohol, and firearms. But no one is suggesting that health professionals can or should make such a decision. The tradeoffs between personal freedoms and reduction of health risks, and the role of the Government in preserving an appropriate balance between the two, remain difficult value questions that must be addressed in public policymaking about prevention of illness and injury.

PERSISTING INEQUALITIES AMID OVERALL IMPROVEMENT

The past two decades have seen a remarkable improvement in health status and access to good health services by Americans of all ages, including children. Indicators of overall progress are numerous and include the following:

- By 1979, the Nation's infant mortality rate had been cut to 13 per 1,000 live births, half of what it was in 1960. The Surgeon General believes it is realistic to reduce the rate to 9 per 1,000 live births by 1990.
- Mortality rates for children 1–4 years old dropped from 109.1 per 100,000 population in 1960 to 68.8 in 1977, and during the same period death rates for children 5–14 years of age declined from 46.6 per 100,000 to 34.6.
- Disease rates for a number of infectious diseases have been cut sharply in a very short time. The incidence of measles dropped from 38.2 cases per 100,000 population in 1975 to 27.1 reported

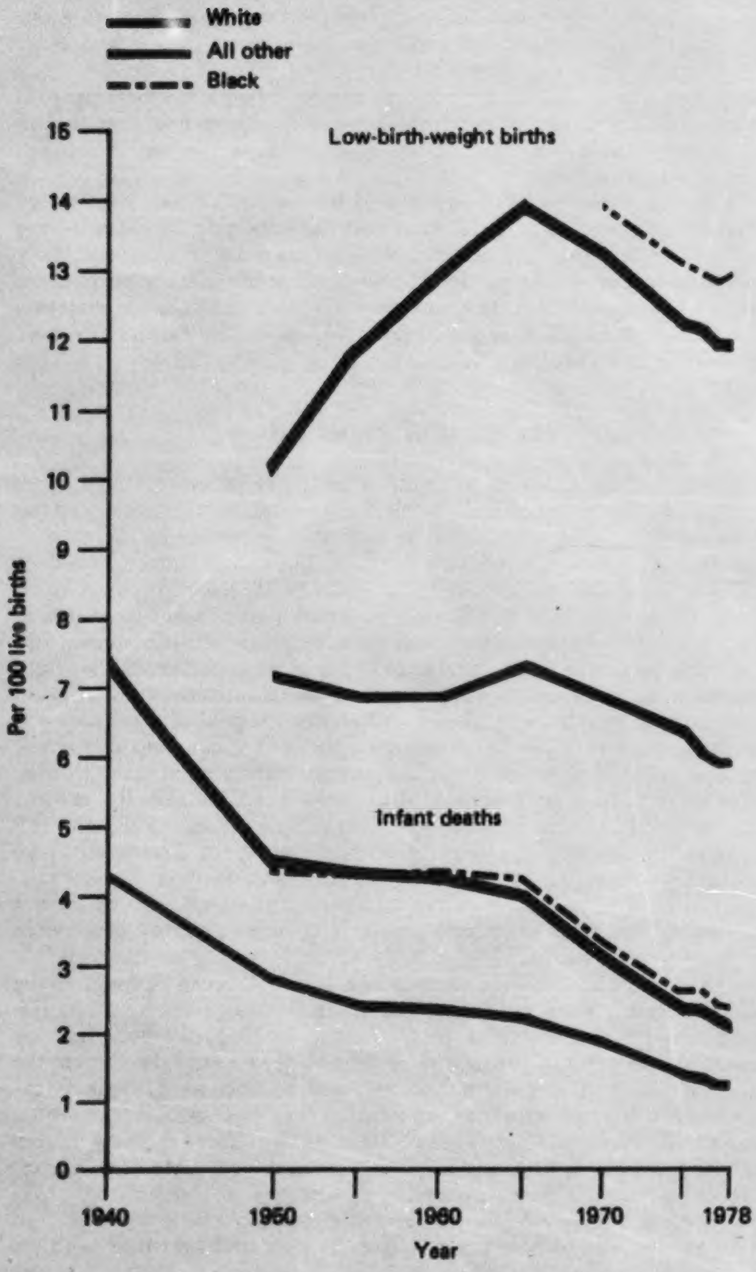
cases in 1978. Reported rubella cases declined from 11.8 per 100,000 to 6.8 during the same period.

- By 1975–1976, less than one-half of 1 percent of all children under 18 (0.4 percent) had never been to a doctor. Some 73.7 percent had seen a doctor within the past year, and 88.4 percent of all children under 6 had done so.
- A child born in the United States today has a life expectancy of more than 73 years, compared with a life expectancy at birth of only 47 years in 1900.

These improvements reflect advances in basic social conditions, environmental health, and medical care. They also reflect the advent of Medicaid and other Government programs, the gradual improvement of organized primary care in poverty areas, and the growing supply of primary health care professionals. Above all, they demonstrate that health status and appropriate use of services *can* be influenced via national policies. In significant measure, present policies are beginning to work. Moreover, advances for mothers and children are especially encouraging in that they have not been a major component of increases in the Nation's health bill. Care for children and pregnant women continues to be a relatively modest investment, and one with major returns.

Although such advances are encouraging, they do not merit self-congratulation or a conclusion that child health should be downgraded in priority over the coming decade. An equally powerful set of facts can be marshaled to demonstrate that recent improvements have not benefited all segments of the child population equally. Indeed, for some groups of children and in some categories of problems, things have improved little or are actually getting worse. It is precisely in those areas of greatest need, and for those populations in greatest need, where health status indicators are most worrisome and services most conspicuously absent (*29*):

- The infant mortality rate of black Americans has decreased over the last decade, but in 1977 it was still 23.6 per 1,000 live births, nearly double that of whites.
- Approximately one-third of all black children are estimated to suffer some kind of nutritional deficit, compared with less than 15 percent of white children. Poverty and race are associated with deficiencies in six of eight specific nutrients.
- In 1977, children under 6 years in the poorest families had almost twice as many bed disability days as those in the highest income category, and a third more restricted activity days. Of children 0–17 years old in the highest income families, 70 percent were reported to be in excellent health, as compared to 41 percent in the lowest income families. Number of hospital days per child under 17 was almost four times as great for the lowest income group as the highest, with average length of stay more than twice as long. Hospitalization rates for minorities were lower, however, suggesting significant barriers to hospital access.
- In 1974, four times as many poor children under 18 reported unmet medical needs as affluent children, with cost and difficulty in getting to a doctor cited by the majority of the poor as the reason for not seeking care.



Infant deaths and low-birth-weight births per 100 live births, according to race: United States 1940-78, selected years

- The high cost of medical care for chronically ill or handicapped children remains a problem for many families. Coverage under the Crippled Children's Services program varies from State to State, so that a seriously ill child may be covered in one and incur catastrophic expenses in another.

These and similar indicators serve to remind us of a persisting gap in health status and use of services between rich and poor, white and minority, educated and noneducated, and also major differences between regions, States, and census tracts.

The Panel believes that equality of access to services is a policy objective of major significance, and that the persisting "problem of the gap" in health status and health service access must be more forcefully addressed in the decade to come. Some progress has already been made. Reduced differentials in infant mortality and physician visits are examples of positive trends. There is good reason to believe that further advances are possible at very reasonable cost.

The Goal of Equal Access

The goal of equal access to health services has proven elusive in part because it has been difficult to define and quantify. Access can be measured by the degree of difficulty in obtaining care or by the number and type of visits to a health care provider. But clearly equal access does not mean equal use, nor should it necessarily be expected to achieve equal health status outcomes. In addition, it is only part of what is needed to solve health problems. Housing, sanitation, nutrition, and other social and economic determinants are undoubtedly far more important in the larger scheme of things as predictors of long-term health outcomes.

What most people mean when they describe the goal of equal access is similar to what is meant in education by the goal of equal opportunity—the equal chance to benefit from interchange with relevant professionals, adjusted in some way to account for level of need. Because low-income children tend to get sick more often than other children, to postpone all types of health care, and to go to hospital outpatient departments and emergency rooms where they receive care which is typically episodic, equal rates of physician visits between them and other children do not necessarily signify equal access to services. Nor is quality of services necessarily the same.

One example of confusion surrounding these points can be found in the widely differing interpretations given to trends in use among Medicaid-eligible and non-Medicaid-eligible children. In 1965, the poor had the fewest physician visits, the near-poor the next fewest, and the affluent the most. By 1975, this pattern had changed to become U-shaped: the Medicaid-eligible poor and the affluent had roughly comparable use rates, and all other poor and near-poor children had less. Does this new pattern signify that equality of access has been achieved for the Medicaid group? Certainly, there has been encouraging movement in that direction, but the answer is probably no, for some of the reasons cited previously. In addition, the new pattern suggests that the poor and near-poor who are not eligible for Medicaid—as well as the 20 percent or more of Medicaid children and women who move in or out of eligibility each year—are at special risk because of sharp discontinuities in access for them and their families.

Unequal Use

Patterns of use are determined by the underlying distribution of illness, difficulties of access, consumer incentives and ability to overcome these problems, incentives to physicians to encourage care, and organizational structures that may or may not accommodate various types of service. These factors are difficult to disentangle. Three central problems—not limited to mothers and children in their effects but of major importance to them—continue to deserve special attention:

(1) There is a strong correlation between high family income and two desirable patterns of care—the appropriate use of preventive care, and the timely use of routine acute care. Conversely, there is a relationship between low income and heavy use of clinical procedures and referrals for specialized therapy. This pattern reflects several disturbing facts: the barriers that keep low-income persons from routine preventive and primary care, the absence of appropriate providers of such care for them and resulting high use of hospitals, the disproportionate amount of serious illness among the poor, and the financial incentives for physicians and hospitals to refer Medicaid eligibles for various forms of specialty care.

The fact that low-income groups do not receive inexpensive and cost-effective forms of preventive care is particularly unfortunate because they have the most to gain from such services. It is serious enough, for example, that in 1977 almost 10 percent of all pregnant women in New York City had no prenatal care, and another 12 percent had care that began in the last trimester. However, in Central Harlem, where infant mortality rates are well above the city average, 30 percent of all pregnant women received inadequate care or no care (*7*).

Once the poor do enter the system, their care tends to be more expensive than it should. On the average, hospital clinics, which perform as much as 50 percent of the care for low-income central city children, are more than twice as expensive as doctor's offices (*30*). Medicaid foots much of the bill, and the rest either comes from the pockets of the poor themselves or else, in the case of growing numbers of medical indigents, from State and local tax revenues. The result has been discontent on all sides.

Especially in the case of children and pregnant women, most of whose care should be routine, inexpensive, and predictable but is highly sensitive to factors of distance and price, the lesson is that organizational structures and financial incentives still do not operate to generate appropriate patterns of primary care. A more decentralized pattern of primary care is required, one which is better insulated against the costs of the hospital sector

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and better able to provide the necessary outreach to foster appropriate early care.

(2) Many studies have shown that individuals with a regular source of care are more likely than others to seek care, even when adjustments are made for need and other factors. In fact, data from a 1976 national survey suggest that the presence or absence of a regular source of care has a greater effect on access to health care than either poverty status or race. It is also the single most important determinant of whether medically "appropriate" utilization of services occurs. Those who have such a source use more preventive care, are less likely to overutilize, and are more likely to express satisfaction with the care they receive (*31*). Despite the many advantages inherent in the continuity afforded by such a source, more than 18 percent of all children from low-income families lack one, compared with less than 6 percent of children from families with an annual income of $15,000 or more. And among those who do have a regular source of care, poor and minority children are less likely to see a particular doctor regularly, and still less likely to have an ongoing relationship with a medical specialist. Only 23 percent of poor families use the same source for sick and well care.

The need to encourage patterns of affiliation with regular care sources among poor and minority families remains a major objective for the coming decade.

(3) Absolute numbers of primary care physicians have been increasing over the past 10 years—from approximately 128,500 in 1967 to 141,000 in 1977, with further increases anticipated over the coming decade. The supply of primary care physicians has also been increasing relative to the number of children and pregnant women, since fertility rates have declined in the same period. However, there still are not sufficient numbers of accessible primary care physicians in areas defined by the Federal Government as medically underserved. Attracting the necessary number of qualified physicians to serve in such areas will require the creation of provider arrangements, whether private or public, which are lucrative enough, of high enough quality, and offer sufficient professional satisfaction to be appealing to health professionals as practice settings.

Although an appropriate ratio of primary care providers to population cannot be precisely defined, the ratio most often mentioned is 1 to every 2,000 persons. By that criterion, 28 million residents of rural and inner city areas live in underserved areas, and 14,000 additional providers are needed to achieve the target ratio. Even if one assumes that in the future more physicians will locate voluntarily in underserved areas because of increased overall supply, nearly 13,000 additional primary care providers will still be needed to serve 26 million persons in 1990 according to estimates of the Federal Bureau of Health Manpower (*32*).

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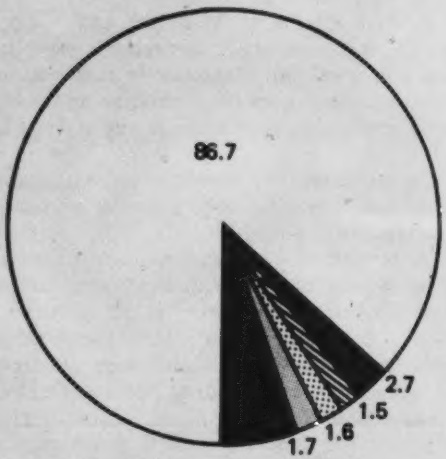
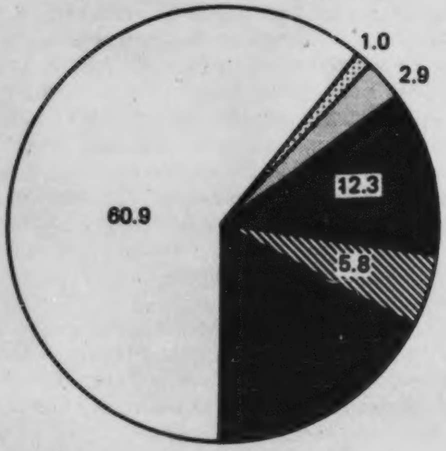


Family income over $15,000 per year



Family income under $5,000 per year

- ■ Hospital
- ▨ With a usual place, but place unknown
- □ Private
- ■ No usual place of care
- ▧ Other
- ▒ Unknown as to whether has a usual place

Usual place of medical care for poor and non poor children: United States, 1974

Financial Barriers

Despite the positive effects of Medicaid and various formula and project grant programs, financial barriers remain responsible for many of the most serious and persistent inequities in maternal and child health care. In fact, just over one-quarter of all children under 18 in families with incomes below $5,000 a year were without any type of health insurance whatsoever—either public or private—in 1976. The majority of all women and children have no insurance coverage for outpatient care. Medical costs relative to income continue to be a greater burden for the poor (11 percent) than the affluent (2 percent).

Private insurance coverage is inadequate in many cases (*33*):

- Less than 30 percent of American children are covered through private insurance for out-of-hospital, physician visits.
- Employment-based insurance plans shortchange coverage for children's needs. Only 15 percent cover children's eyeglasses; 9 percent, preventive care; and 32 percent, children's dental care.
- More than one-half of the private insurance plans fail to cover prenatal care; 45 percent exclude postnatal care; 90 percent exclude family planning; and about 50 percent leave major gaps in covering newborns during the first days of life.

There is also a widespread but erroneous assumption that Medicaid has pretty much guaranteed the poor access to health care. Actually, Medicaid covers only about three-quarters of the poor, excluding some 7 million children who are poor according to Federal criteria. Medicaid eligibility and coverage varies widely from State to State, including nearly all poor and near-poor individuals in a few States but only a fraction of the poor in others. In some States, for instance, Medicaid covers only about 10 percent of all poor children and even for that tiny minority, pays only about 10 percent of medical expenses (*30*). Nineteen States do not cover maternity care of women during their first pregnancy. Moreover, because in many areas Medicaid fee schedules are very low and the lag time for reimbursement is high, many physicians simply do not find it in their interest to participate.

Among the 50 jurisdictions with Medicaid programs, 21 have decided not to include the medically indigent. Such families—the poor and near-poor—typically use very few health services, even though they share with their Medicaid-eligible counterparts an above-average need for such care. Some States that limit Medicaid eligibility or fail to index ceilings to account for inflation are finding that they avoid one form of increased expenditures only to incur another when the poor and near-poor turn up at hospitals or public health clinics as indigents.

In many of the Nation's larger and older cities, the problem of financing health care for the indigent is only one aspect of a broader fiscal crisis. As the tax base of such cities erodes, municipal governments are increasingly hard pressed to make ends meet. Chicago is a good example in this regard. The city has an eroding tax base, but demand for services is up. Lower income minority families now make up 42 percent of the city population, an increase from 23 percent in 1960. Rates of unemployment are considerably above the national average. Predictably, the supply of health services through free-standing clinics, schools, and hospitals has been under great pressure as available city funding shrinks but needs increase (*34*).

One result is that the Federal dollar has grown in significance as a determinant of the availability of health services for the poor. Overall public spending doubled in Chicago between 1970 and 1978, but the city's own budget increased only 58 percent. By 1978, the Federal Government was spending 4.3 times more than City Hall on city services. Nearly all Federal funds have an influence on maternal and child health care. When general revenue sharing is cut, school health services suffer. When CETA workers are reduced in number, the city's health clinics suffer. Health care is not an independent policy concern, but part of a wider political process.

Health services for children, especially those of a preventive and primary care nature, are frequently the first to be cut in a budget squeeze. In New York City, the health department budget was cut from $50 to $40 million between 1974 and 1978, with an added loss of $20 million in matching funds. Child health and pediatric treatment centers, school health programs, dental health projects, clinics for eye exams and venereal disease treatment were all among the services trimmed (*35*). There was a similar disproportionate impact on children's health services in the wake of the adoption of tax-slashing Proposition 13 in California in 1978. Because it is the poor and near-poor who depend most heavily upon publicly supported services, they bear the brunt of such fiscal cutbacks.

THE CHANGING PROFILE OF HEALTH NEEDS

A third broad concern results from the fact that the profile of health problems among the Nation's children and pregnant women is changing. Advances in public health and medical care have led to striking declines in infectious disease, nutritional deficiencies, and gastrointestinal disorders, which were the major causes of illness and death in children 50 years ago. Although these problems still affect significant subpopulations, their continued existence reflects a failure to apply our knowledge rather than ignorance of appropriate solutions.

Parallel to the decline in traditional childhood disease, however, has been an increase in attention and concern directed toward such problems as accidents, child abuse and family violence, learning disabilities, developmental lags, school adjustment problems, issues of adolescent sexuality, excessive risk-taking, substance abuse, and the social and emotional aspects of handicapping conditions. In a recent study of seven primary care facilities, the proportion of children recognized as having behavioral, educational, or social problems ranged from 5 to 15 percent, and was substantially higher among low-income children (*27*). Similarly, it has been estimated that 25 percent of physician referrals for children today are related to psychosocial or behavioral problems (*36*). Other manifestations of such problems, which some have termed "the new morbidity," (*37*) include the following.

- Although mortality rates for all other age groups have declined steadily since 1900, death rates for adolescents and young adults

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aged 15–24 have actually gone *up* since 1960, largely as a result of the growing toll from accidents, homicide, and suicide.

- Suicide is the third leading cause of death among teenagers and young adults aged 15–24; homicide is the leading cause of death among black teenagers and young adults, accounting for 30 percent of deaths in this age group.
- Up to 1 million children each year are the victims of child abuse and neglect. Between 2,000 and 5,000 die annually at the hands of their parents or caretakers.
- Approximately 11,000 girls under age 15 give birth each year, incurring significant medical, psychological, and economic risks.
- Between 1975 and 1979, the proportion of high school seniors reporting alcohol use within the past month climbed from 68 to 72 percent; marijuana use, from 27 to 36 percent; and cocaine, from 2 to 6 percent.
- In 1979 almost 13 percent of women aged 12–18 were regular cigarette smokers, as compared to 8 percent in 1968.

Only some psychosocial and behavioral problems are new or increasing in prevalence. More attention to such issues also has resulted because diagnostic categories have become more varied and complex with the growth of the health and social service professions, and because more physicians have become aware that physical, psychosocial, and behavioral factors are closely intertwined as they influence short- and long-term health outcomes. This last point is particularly important, and has three major aspects.

First, it is almost self-evident that behavior is one of the principal determinants of health status. This is especially true for children, both because so many behavioral patterns established in childhood affect long-term health outcomes in adulthood, and because so many of the immediate dangers to children are those related to risk behaviors or situations that admit of behavioral but not medical solutions. Children's physicians and other health professionals are aware that the best form of contemporary "well-child care" is one that fosters good basic habits of hygiene, nutrition, self-concept, and personal judgment on numerous health related matters. None of this can be accomplished by giving an injection or writing a prescription.

Second, much of child illness has a psychosocial or behavioral component. For example, both children with various types of handicap or chronic illness and their families require intensive support well beyond traditional medical care if the children are to function effectively in schools and the community. To cite a different type of example, some children exhibiting physical symptoms in fact have a psychological problem. Psychosomatic illness is still not well understood, but various forms of psychosomatic diagnosis have become routine, affecting approximately 8–10 percent of children (27). Typical symptoms include abdominal pain, headache, constipation, diarrhea, and other common physical complaints.

Finally, some forms of mental illness and deviant behavior among children have organic causes that may not be immediately apparent. The genetic contribution to some types of childhood psychosis and other forms of severe damage to the central nervous system is well established. More pervasive and subtle, however, are organic effects of lead poisoning, and other environmental insults, that can affect cognitive development and behavior (*38*).

In summary, it is important to distinguish among health-related behaviors, psychological aspects of disease (including behavioral problems of the handicapped), and the organic determinants of mental health or mental illness. But each of these is an important element in the new profile of child health need.

Children's Problems by Age Group

Good data on the incidence and prevalence of behavioral and social conditions are hard to come by in this country, partly because many of the relevant diagnostic categories are somewhat imprecise and partly because no national survey data exist at any level of detail on the topic. Smaller studies have succeeded, however, in establishing a causal or predictive relationship between some psychosocial or behavioral problems and various background factors. Basic demographic and family-related factors are among the strongest predictors of many conditions.

A good deal of uncertainty remains about how various prenatal and perinatal events influence the subsequent development of the child. But it is generally agreed that very low birth weight is among the most significant predictors of later neurological abnormalities and various cognitive and behavioral deficits. Considerable attention also has been given to interactions between mother, father, and infant at birth and shortly thereafter. Some believe that observation of early mother-infant interaction in the maternity hospital is a valuable mechanism for estimating psychosocial risk (*22*). Others have focused on teaching parents how to interact positively with their infants in the hospital (*39*). Shorter maternity hospital stays for mothers mean that these and similar services are more difficult to organize than they once were, suggesting an important reason for subsequent home visiting.

Among preschoolers, physical and psychosocial growth are very closely related. The recent report of the Task Force on Pediatric Education shows that about 14 percent of mothers of children under 5 surveyed in telephone interviews reported their children had a growth and development problem of some sort, and 10 percent reported a behavior or discipline problem. But only about one-half the mothers had discussed these problems with a professional (*40*).

Once children begin school, many of their psychosocial problems are identified and defined in relation to schooling. Typically, boys are found by observers to have higher rates than girls of problem behavior—withdrawal, learning disabilities, truancy, aggression, and delinquency. Some problems may simply reflect high levels of energy, exuberance, or dislike for school. But behavior that leads to low achievement, falling behind grade level, or dropping out of school is of major concern. More than one-fourth of boys and one-sixth of girls still in school during their mid-teens have dropped below grade level, and the rates are much higher for minority students—40 percent for boys and 30 percent for girls (*41*).

Recent evidence from the 1979 Report to Congress on the implementation of P.L. 94–142, the Education for all Handicapped Children Act, also suggests that of the 3.6 million handicapped children being served under the provisions of the Act, a large percentage have problems that are likely to include a major psychosocial component. In 1978, less than 9 percent of those served had orthopedic, auditory, or visual impairments; this is compared to 33 percent who were speech impaired, 25 percent who were mentally retarded, and almost 8 percent who were emotionally disturbed (*42*). One effect of this program and other special educational efforts in schools has been to increase the demand for accurate diagnosis of school-related problems. The role of physicians and health professionals in this process still is not well defined, athough spillover effects have resulted in increased demand for health services of all kinds.

There is a danger that a heightened awareness of the psychosocial problems of school-age children may lead to inaccurate or inappropriate labeling of youngsters. Definitions of such problems do not always reflect well-established diagnostic criteria. Some States, for instance, are more likely than others to label a child retarded. California, which has suspended school-related IQ testing, reports fewer than 1 percent of its school children are mentally retarded. But South Carolina and certain other southern States report figures closer to 4 percent. Such discrepancies may say more about local labeling practices than they do about the "true" prevalence of mental retardation among school children in those States (*42*).

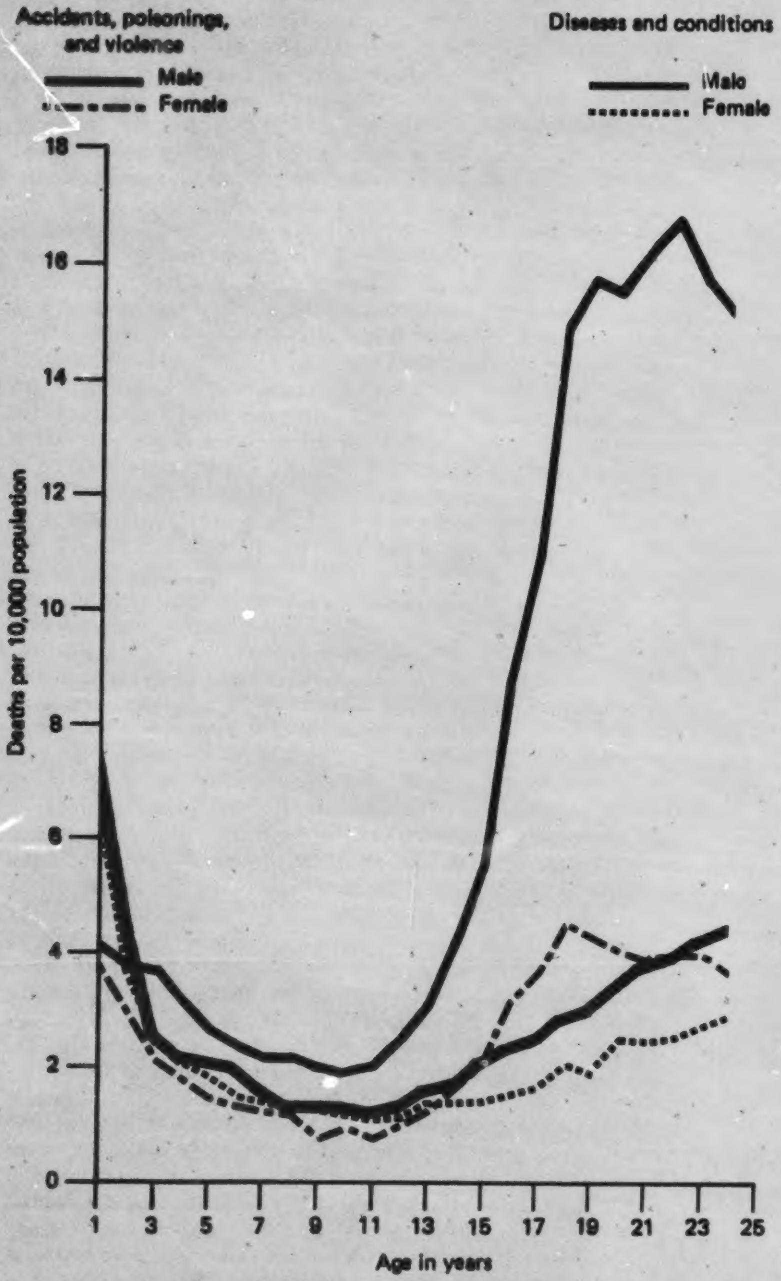
Behavior and learning problems that first appear in grade school often persist and grow worse in adolescence. In addition, adolescence introduces a number of psychosocial issues in its own right, prompted by a quantum jump in cognitive development, the discovery of sexuality, and the temptation to engage in various risk-taking and potentially self-damaging activities. Problems of the Nation's youth are a time-honored topic and one about which every generation worries. Thus, recent high levels of concern about adolescent behavior should not be taken to mean that something is seriously wrong with America's adolescents. But in reviewing the evidence on causes of death and disability among adolescents, most are clearly related to behavior rather than disease.

Implications for the Health System

The new salience of behavioral and psychosocial problems presents a major dilemma for primary health care providers. If they are serious about their mission it is not sufficent to retrench, ignore these major health problems and determinants, and focus only on infectious disease. On the other hand, if they hope to have any real influence on behavioral and psychosocial problems, traditional practice patterns will have to be altered. Policymakers in turn must provide incentives for appropriate service delivery structures and modes of service financing.

Some implications of the new emphasis are the following:

(1) The "new" health problems cannot be treated in isolation from the child's home, school, and community environments where behavioral and psychosocial problems begin and where their



Death rates for persons 1-24 years of age, according to age, sex, and cause of death: United States, 1976 consequences are felt most keenly. Health professionals will not be effective if they fail to understand the major influences in the child's life and interact cooperatively with parents, teachers, and other professionals and service providers. Moreover, without such close coordination the potential is great for duplication of effort, misclassification or multiple and conflicting classifications of children, and efforts at cross-purposes among various professionals, including physicians. Prototypic of the need for coordination between health professionals, parents, and the schools is the requirement of P.L. 94–142 for the evaluation of handicapped children and preparation of individualized educational plans for each. The potential for useful physician input in this process is high. Another example is in health education, where counseling by the health care provider should correspond closely to what is taught in the school and promoted by the family.

Because the family is the principal socializing agent for children, health providers need to understand the sources of stress and support for a child's parents. The recent resurgence of interest in home visitors and other means of offering services within the family setting is one reflection of this fact. Similarly, there is a need to build on the strengths of the home environment, which health services do not often do. Two-thirds of teenage mothers live with their parents, for example, and are often denied publicly financed services because they are members of intact family households (*43*).

(2) The new importance of behavioral and psychosocial elements of care also reminds us that physical health problems cannot be treated in isolation from mental health problems. Categorical approaches to mental health services tend to disguise the fact that most primary health care providers are also providers of mental health care. It has been reported that up to 60 percent of all encounters for mental health problems take place in the general medical care system (*32*). Primary care physicians without the ability to diagnose psychosomatic illness, exceptional stress, the effects of inappropriate health behavior or the psychological consequences of physical illness are not likely to be effective in responding to physical or mental health problems.

(3) The definition of health-related services that should be routinely provided in organized primary care settings needs to be expanded to include various services that are not a traditional part of curative medicine and have often been seen as "boundary services" to be provided by others. One good example is outreach, case management, and social services to families with special needs to ensure attention to preventive measures in the home, appropriate use of preventive services, and assistance in obtaining services to make possible a coherent and continuous response to the child's needs. Proper treatment for learning disabilities may not require drugs but rather effective cooperation with teachers or parents to change practices in school or at

home. Similarly, nutrition counseling may require more than simply instructing the parent during a brief well-child visit. Or, consider the example of the adolescent girl who gets pregnant because she does not see any more attractive alternatives in her life. This is not a medical problem, but has profound health implications.

Because many "boundary" services to enhance prevention and health promotion tend not to be covered by third-party payers, there is little incentive to provide them. Implications for the financing of services are particularly tricky because policymakers should probably not offer open-ended reimbursement for such services without careful control of quality and effectiveness. Conditions under which"boundary" services should be financed are discussed more fully in chapters 5 and 9 of the report.

Whatever the payment mechanism, "boundary" services will play an increasing role in health care as the Nation moves toward a greater emphasis on prevention and health education. It is noteworthy that State health agencies—when asked to list actions that should be given highest priority to further reduce infant mortality—placed first on their list an increase in consumer education about general health care, parenting skills, accident prevention, nutrition, and the effects of alcohol and drug abuse during pregnancy. They also emphasized the need for sex education in schools and support services such as transportation (*44*).

(4) The changing health needs of children imply changing requirements for physicians and other health care personnel. This fact has led to a rather painful reassessment of training priorities by the relevant health professions, especially pediatrics.

As it has become clear that the training of general pediatricians is inadequate for many of the child health problems they most often encounter, the profession has moved assertively to address the problem. The Task Force on Pediatric Education, whose recommendations already have taken effect in many medical schools, recently offered a far-ranging vision of needed reforms in the training of general pediatricians. Similar reforms are contemplated by family practice, obstetrics and gynecology, and nursing, to name only a few of the relevant health professions.

These reforms will have a long-term effect only if fundamental incentives and organizational structures in medical education and practice are changed. At present, for example, only a few residency programs offer sufficient opportunities for community-based training in primary care. In one major city hospital, the chief of pediatrics told the Panel that his residents had very little experience with well children and had great difficulty when they set up practices of their own handling day-to-day problems of mothers and children, such as giving advice on breast-feeding (*45*).

The problem of inappropriate training is made more acute by the projected increase in numbers of pediatricians and other primary care providers. This trend and its implications are discussed in chapter 12. An increased ratio of health care professionals to children in 1990 will matter little if these personnel are not equipped to meet the real health needs of mothers and children.

Finally, the new profile of need has implications for manpower mix and coordination among various types of health-related personnel. Because behavioral and psychosocial needs are not the exclusive purview of physicians—indeed physicians may not be best equipped to deal with some of them—there is a need for team approaches using nurse practitioners and other nurses, nutritionists, social workers, psychologists, teachers, and others. It would be a major policy error to have expensive professionals performing services that should be inexpensive to provide. The history of insularity within the various health professions and the absence of shared training opportunities are major obstacles to effective care. Service structures and incentives will need to be changed before it is realistic to expect effective primary care in all of the Nation's communities during the 1980's.

THE FAMILY AND CHILD HEALTH

A fourth major concern expressed frequently to the Panel was that the health care system does not adequately recognize or support the central role of the family in child health, and that the American family itself has changed dramatically over the past two decades, with possible serious consequences for the health and well-being of the Nation's children. This same concern was reflected in the agenda of the National Family Impact Seminar and the 1980 White House Conference on the Family.

There is no greater influence on the health of any child than the family. From conception on, a child is dependent upon his or her mother and other family members not only for the physical necessities of life—food, shelter, clothing, and protection from harm—but also for the emotional support and intellectual stimulation needed for healthy growth and development. It requires no great expertise to recognize the importance to any child of a secure, loving, and stimulating family environment. But it is important to realize that a family's ability to support and nurture a child can be affected either positively or negatively by a number of external circumstances, including the presence or absence of adequate income, decent housing, a safe neighborhood, and close and supportive relatives and friends.

Our growing recognition of the psychological and social components of health has enhanced our awareness of the family's importance. An inadequate home environment can have severe adverse consequences on the health of a child. Indeed, certain clinical syndromes—accidents and ingestions, pica (relentless craving for nonfood substances), failure to thrive, child abuse and neglect—can threaten a child's survival. Such

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illnesses appear to be linked with family stress, including such problems as unemployment, drug dependency, marital difficulty, poor housing, illness in one or both parents, and poverty.

Research over the past three decades has consistently pointed to family stress and disorganization as an overriding factor in the development of behavior disorders and social pathology (*46*). Much of this same research has shown that the forces of disorganization arise not so much within the family itself as from the outside, from the circumstances in which the family finds itself and the way in which those circumstances shape the family's way of life.

The Family and Health Providers

The family is not only the principal influence upon a child's development, it is also the intermediary between the child and the outside world, including the health care system. It is parents who decide when to seek health care for a child, where to seek it, and from whom. It is parents who provide the lion's share of all care to a sick or injured child.

Health providers can support, encourage, and enhance the competence of parents in their role as caregivers, or they can directly or indirectly undermine and denigrate it. The physician who brusquely orders a mother to give her child penicillin four times a day for 10 days for a sore throat without explaining why it is important to do so—even after the throat is no longer sore—is helping neither mother nor child, for very few parents will follow the instructions faithfully in the absence of such explanation. Health providers who make no effort to help parents understand what can reasonably be expected of a child at various ages, and how the parents can help the child master new skills, are likewise failing to support caregiving competence.

Fortunately, there are examples of ways in which the health care system can and does promote and enhance family competence in caregiving. There has been an enormous movement, over the past decade or so, toward family-centered maternity care, an approach that has been formally endorsed by virtually all of the professional societies whose members are most deeply involved in the care of pregnant women and their babies both before and after delivery. The precise components of such care—and the professional participants in it—vary from one institution to another, from one community to the next. But at the core is one guiding principle—that childbirth education, labor and delivery, and care for a newborn are enhanced when other family members, especially the father, become active participants along with the mother and when health professionals encourage rather than restrict early and frequent contact between the newborn infant and its parents.

A second example of health care practices that enhance the role of the family can be found in the increasingly widespread provision for parental participation in the care of hospitalized children. Allowing parents or other adult family members to be with a child during diagnosis and treatment procedures, and overnight if the child is hospitalized, both eases a child's fears and enhances the parent's ability to understand what is happening to the child and to assist in the care of that child.

Finally, on a somewhat different level, there is evidence that early childhood development programs, which include a health component, can improve both family functioning and competence and the overall health of children. A 1979 General Accounting Office study showed that such programs "can result in reduced health, social, and educational problems in young children," and noted that those problems, left unattended, "are expensive and difficult to overcome in later years." According to the GAO report, developmental programs for low-income children were most effective when the child entered at an early age and when parents were closely involved in the program. Particularly effective were Head Start Child and Family Resource programs of the Department of Health and Human Services (DHHS) that utilize home visitors to coordinate health, education, and social services for enrolled families (*21*).

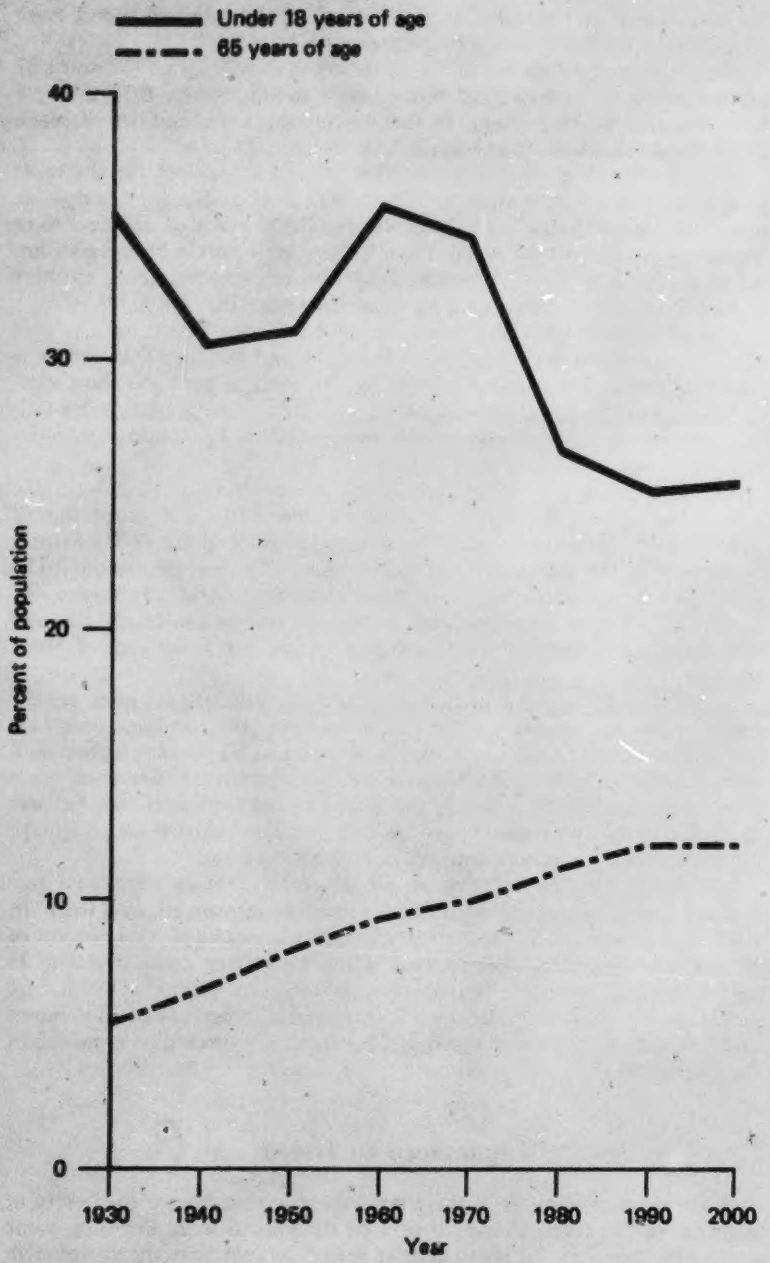
Changing Family Composition and Circumstances

Some pronounced changes have occurred over the past two decades in the composition of American families and the circumstances in which they live. Some of these changes may have significant consequences for the health and well-being of the Nation's children, but their full impact is not yet clear in most cases and is difficult to quantify in any event.

The past decade has seen an increasing diversity in living arrangements among Americans, both in the composition of households and families at a given time and in the experiences of individuals over their life course. Although three-quarters of the population still live in married couple households, and most still live for at least some of their lives in nuclear families, the stereotypic two-parent family with the father working and the mother raising children is increasingly a thing of the past. Today's family forms include men and women living alone, single parents, two-worker families, retired couples, and families whose children have moved away. In the coming decade, these family forms will constitute a growing segment of the Nation's households. Likewise, as people move through the life cycle, they are likely to have more diverse experiences—fewer years spent in nuclear families, more changes in types of households, more living apart from close relatives, and a wide variety of family relationships.

The 1970's witnessed a steady decline in the proportion of families that include children, in the number of children per family, and in the number of children overall in the United States. Although one might think that fewer children in each family and in society as a whole may make it possible to devote greater care and attention to those children we have, there is the danger that families with children will become increasingly isolated and that the Nation as a whole will devote less—not more—of its social policy attention to that minority of the population that is young.

At the same time that the number of children has been declining, the types of families in which they grow up have been changing. Although only 4 percent of all children do not live with any parent, and the vast majority live with two, the proportion who live with just one parent has risen from 9 percent in 1960 to 12 percent in 1970 and 19 percent in 1978. By 1990, it is estimated that 25 percent of all children will be living with



Population under 18 years of age, and population 65 years of age and over, per 100 total population: United States, 1930-2000, selected years just one parent and that nearly one-half of all children will spend some part of their childhood with a single parent (*47*).

These percentages are much higher for black families. In 1970, some 32 percent of black children lived with a single parent, and by 1978, this rate had increased to 45 percent. In fact, about the same number of black children now live with one parent as with two.

The increase in single-parent families can be attributed, for the most part, to an increase in marital separation and divorce. Since 1950, divorce rates have more than doubled for women 20–29 years of age and have tripled for women 30–44 years of age. Other single-parent households are the result of out-of-wedlock childbearing. One of every five single mothers in New York City, for example, has never been married (*48*).

Single-parent families have lower incomes than two-parent ones, in part because they have only one wage earner, in part because that earner is nearly always a woman and women on the average earn less than men, and in part because women who head families find it difficult to work full-time while also shouldering sole responsibility for child care and housekeeping.

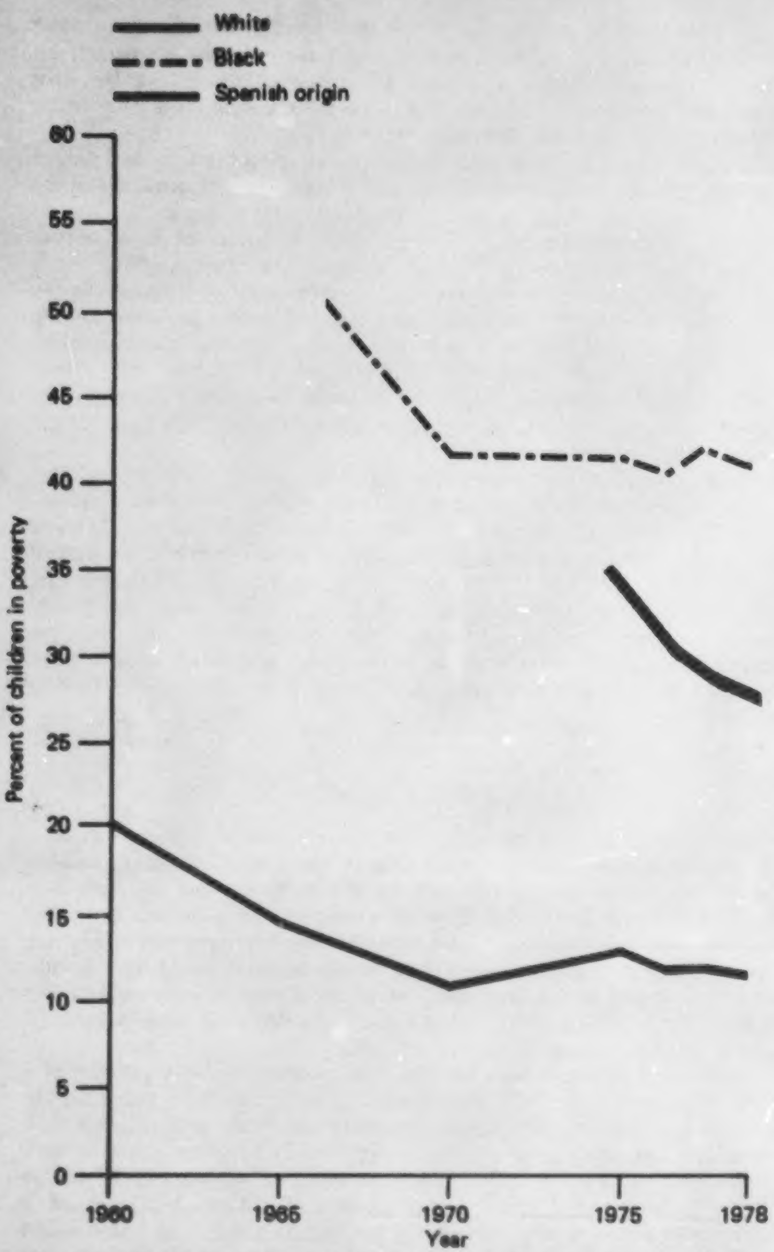
Although poverty rates in the United States dropped sharply in the 1960's, they remained relatively constant in the 1970's. The proportion of children living in poverty actually increased slightly in the 1970's, largely as a result of the increase in the numbers of single-parent families. The plight of black and Hispanic-American children is especially severe—41 percent of all black children and 27 percent of Spanish-origin children were living in poverty in 1978, compared with just 11 percent of white children.

In many parts of the United States, Spanish-speaking families are the fastest growing minority. The birth rate of the resident Hispanic population is more than twice that of whites and 60 percent higher than blacks (*49*). In seeking health services, women and children in these families must confront not only the financial and organizational barriers that other poor and minority groups face but also cultural and language differences that impede meaningful communication.

In addition to the increase in single-parent families, the past two decades saw a major upswing in the proportion of mothers who work. In 1979, 54.5 percent of all mothers of children under 18 and 45.4 percent of all mothers of children under 6 were in the labor force, compared with 28 percent and 19 percent, respectively, in 1960. In short, by 1979, 51.4 percent of all children under age 18 years and 42.6 percent of all children under 6 had mothers who worked. This trend is expected to continue in the 1980's (*50–52*).

Relevance to Health

While the implications of these demographic changes for the health of mothers and children cannot always be pinpointed with precision, some are fairly apparent. In particular, it seems evident that the increase in single-parent families has some ominous implications for child health since such families generally have low incomes and poverty is the single



Percent of children and youths under 18 years of age in poverty, according to race and Spanish origin: United States, 1960-78, selected years biggest predictor of poor health in this country. Further, the unrelenting stress experienced by a woman trying to raise a family by herself on severely limited resources can have a detrimental impact on her own health and that of her children. The same is, of course, true of a single father, although he is less likely to be poor.

Stress is also a serious problem for working mothers in two-parent families, for such women typically continue to carry the major share of the child care and housekeeping load at home even as they put in full days on the job outside of the home. Indeed, stress is perceived as a serious problem by most American families, whatever their composition, and is believed by a number of experts to be a significant contributor to the rising incidence of psychological, social, and behavioral problems among children. Such problems as drug abuse, alcoholism, child abuse, suicide, homicide, and other forms of violent or aberrant behavior are almost certainly caused at least in part by family stress. In the 1979 General Mills American Family Report, 8 out of 10 respondents indicated a need for less stress in their daily lives (*53*).

Another result of increased participation in the work force by mothers is that parents are now spending less time overall with their children. Indeed, one study of sixth graders in the Bay Area / San Francisco-Oakland found they spent less than 1.5 hours with a parent between the end of school at 3:00 p.m. and bedtime at 10:00 or 10:30 p.m.—and part of that was in front of a television set (*54*). Other studies have shown that children are more reliant on their peers than they were 10 or 15 years ago, and that such attachments seem to be more a product of a lack of attention and concern at home than of any positive attraction to the peer group (*55*).

Child Care

The increase in the proportion of mothers in the labor force has been accompanied by an increase in the need for child care. Information about care arrangements tends to be sketchy and outdated, but available data have consistently shown that informal arrangements in or near the home predominate. For example, U.S. Census Bureau data for 1974–1975 show that 55 percent of all children 3–6 years old whose mothers worked full-time were cared for in their own homes by a parent, relative, or other babysitter; 36 percent went to the home of a relative or other babysitter, and just 6 percent were in day care centers.

Schools, of course, offer a form of "child care" for the larger part of a typical working day. Fully 99 percent of all children 6–15 years old are enrolled in school, along with 90 percent of 16- and 17-year-olds. Preschool enrollments have jumped significantly in recent years as well, partly because of the need for child care but also because of the benefits they offer to young children. The proportion of children 3–5 years old in preschool increased from 13 percent in 1966 to more than one-third in 1978. About 83 percent of all children 5 years of age were in kindergarten in 1978, compared with 68 percent in 1967 (*47*).

Although some people have expressed concern about the possible negative consequences that day care may have on child development, a

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recent review of the research literature on the subject offers no support for this view (56). Existing research indicates children of working mothers develop just as well on the average as those whose mothers remain at home and show no difference in the rate of psychological disorders. In general, harmony and parental love within the family are what count in meeting a child's needs, regardless of work and care arrangements. More data are needed, however, on the adequacy of informal care arrangements and day care for infants.

In concluding this brief section regarding health promotion as it relates to American family life, the Panel wishes to take note of—but not take sides in—the highly emotional debate which has surrounded all recent policy determination aimed at families. The family has come to be a symbol both for the most conservative Americans, who see it as a private sanctuary and the building block of a free and libertarian society, and for the most liberal, who see it as an entity which is highly interdependent with other elements of the social and economic order and in need of routine social support, both private and public. We believe that both of these visions are right, and that they are not mutually exclusive. It makes little sense to choose one of them simply in the interest of ideological purity. We hope that in the future, policymakers will weigh the impact of policies on the family according to their particular merits or demerits rather than the broader emotional responses they evoke.

FRAGMENTATION AND DUPLICATION

The Panel's fifth and final major concern involves fragmentation and duplication of effort among programs, policies, and providers. Evidence of this problem was frequent in our hearings, site visits, and expert consultations—often with reference to gaps and overlaps in service, and resulting inequities and inefficiencies. Analytic understanding of the origins of fragmentation and realistic proposals for significant reform were much harder to come by, however, perhaps because of the sheer complexity of the phenomena being criticized. All agree that it is a serious problem, but particulars of the problem and proposals for its solution tend to differ depending on whether the beholder is a member of Congress, a Federal bureaucrat, a State or local agency representative, a service provider, or a parent.

Four kinds of fragmentation give cause for concern: among Federal programs and policies, among local delivery units, among levels of government responsible for orchestrating health programs, and among various categories of personnel working in maternal and child health and health-related fields.

Federal Programs and Policies

Since the 1960's, there has been a tremendous increase in the number of Federal programs and policies relating directly or indirectly to maternal and child health without any comparable increase in coherence or overall policy direction for these programs. There are at present anywhere from

21 to more than 100 relevant Federal programs, depending on how broadly maternal and child health is defined (*57*). The very difficulty in deciding how many programs should be listed indicates just how complex the fragmentation issue has become.

Prior to the 1960's, major Federal involvement in maternal and child health was largely limited to Title V of the Social Security Act, in effect as a formula grant program since 1935, and to the school-based food supplement programs of USDA which commenced in the 1950's. The last 15 years, however, brought the enactment of Medicaid, the Community Health Centers, Project Head Start, increased support for day care, family planning, compensatory education, and extensive new programs for the handicapped—to name just a few of the biggest programs.

Oversight and administration of the major maternal and child health programs are spread among a variety of congressional committees and executive branch agencies. On Capitol Hill, authorizing responsibility rests primarily with the Interstate and Foreign Commerce Committee and the Ways and Means Committee in the House, and with the Labor and Human Resources Committee and the Finance Committee in the Senate. Major health-related programs in agriculture and education lie outside the purview of the principal health subcommittees. In addition, the Appropriations and Budget Committees on both sides of the Hill wield major influence over all maternal and child health programs.

Executive branch responsibility is similarly dispersed, with at least 10 Federal agencies involved in interpreting and carrying out relevant legislation. Many of the major programs are lodged in DHHS within which authority is divided along several different lines.

- Within the Public Health Service (PHS), the Office for Maternal and Child Health (OMCH) administers the Title V program and several smaller ones including the Sudden Infant Death Syndrome, Hemophilia, Genetic Disease, and certain aspects of the Supplemental Security Income program. Other parts of the PHS are responsible for Community Health Centers, the Rural Health Initiative, Migrant Health programs, and Family Planning, and still others handle childhood immunization, health education and research.
- Although the PHS is responsible for most maternal and child health programs and policies, the Health Care Financing Administration (HCFA) administers Medicaid, including EPSDT.
- Separate from the programs and policies of both the PHS and HCFA are those of the Office of Human Development Services, which administers Title 20 of the Social Security Act and also includes the Administration for Children, Youth and Families, which in turn administers the Head Start program, the Children's Bureau, and various youth programs.

All of this division of responsibility occurs just within DHHS; a number of other major programs lie in completely different departments such as Agriculture (school lunch and breakfast programs), Education (the Education for All Handicapped Children program), Transportation (traffic safety programs), Labor (occupational health programs), Justice (juvenile delinquency programs), and Defense (CHAMPUS). There is at present little unity, no overarching authority, and only a minimum of joint planning among all these programs and agencies.

Maternal and child health advocates have been particularly concerned by the downgrading and dismembering of the Children's Bureau, which for years was the focal point for national policy toward children. Maternal and child health was broken off from the Bureau at the end of the 1960's and subsumed under the PHS, and a variety of additional changes have diffused authority and responsibility for it and other children's programs. There are many who would like to see a single focal point for maternal and child health recreated within DHHS. Absence of such a focal point has been further brought home by the fact that two of the most consequential legislative initiatives of the 1970's—the passage of P.L. 94-142, the Education for All Handicapped Children Act, and the expansion of the Supplemental Food Program for Women, Infants and Children (WIC)—have taken place entirely outside the DHHS orbit.

But it is easier to criticize the situation than to simplify it. The current array of programs is no accident. It evolved over time from a complex interaction of constituency pressures, judicial decisions, legislative enactments, and administrative actions. Each program has a unique history and purpose, and each has legislators, bureaucrats, and interest groups who wish to sustain or expand it. As two major recent studies of Federal policy toward children make clear, advocates of increased Federal expenditures for mothers and children have generally found it easier to win support for programs focused on special needs or target groups than to seek broader policy reforms (*58, 59*).

There are, of course, significant benefits to pluralism. Having more than one approach to a problem can offer more than one avenue for success. A single big agency, furthermore, is not necessarily more efficient than a number of smaller ones. However, having said that, the Panel nonetheless believes major changes must be made to restructure management of health programs for mothers and children so they can function as a coordinated Federal-State-community system. This topic is explored more fully in chapters 10 and 11.

Local Providers

Another concern relates to the wide array of primary care arrangements in many communities; the lack of coordination among them; the pattern of multiple use by consumers; and barriers to appropriate use created by differences in the scope of services, eligibility, hours of availability, extent of backup care, and other characteristics of these arrangements. Especially in large metropolitan areas, these problems are common. Private office-based practitioners, clinics in hospitals, health departments and schools, Head Start programs, family planning clinics, public comprehensive care centers and more exist in close proximity to one another and almost never operate collectively as a health care "system."

To a large extent, the familiar two-tiered pattern of care still predominates in most urban and suburban neighborhoods, with poor mothers and children receiving care from hospitals and public clinics and more affluent ones visiting private office-based physicians. Distinctions between private and public providers have been somewhat blurred by the advent of Medicaid; almost 85 percent of general practice pediatricians, for example, receive at least some of their income from this and other public programs (*60*).

Once again, it is easier to describe the problem than to prescribe solutions. The Nation is committed to pluralism in health care, with a mixed private-public system and the right of consumers to choose among a variety of provider arrangements. The historic division of services between preventive care in public health clinics and acute care in other settings evolved partly as a way of avoiding direct competition between public and private providers. Newer public comprehensive care programs have been targeted to particular income and age groups in an effort to reach those in greatest need, only inadvertently creating inefficiencies through conflicting eligibility rules and copayment requirements. Likewise, many hospitals did not set out to provide primary care but found it necessary to do so as a result of their ready accessibility, around-the-clock operation, and responsibility to serve as a care source of last resort to the poor.

Although it is admittedly difficult to overcome fragmentation at the local level, it can in fact be done, as a few communities have demonstrated. Cambridge, Mass., for example, once suffered from exactly the sort of multiplicity and duplication of programs found in so many urban communities today. However, in 1967 the city council established a single health, hospitals, and welfare agency under a commissioner who in turn delegated responsibility for municipal child health services to the the Community Hospital, Department of Pediatrics. With all relevant public budgets controlled by a single source, a new system of school-based primary care units was set up to provide both sick and well-child services. It is still doing well today, offering integrated care to children at a per child cost significantly below that of other providers (*61*).

The Denver Department of Health and Hospitals has likewise overcome the fragmentation problem by pooling funds from a variety of Federal, State and local sources to create an impressive system of neighborhood comprehensive care clinics.

Current examples of service integration or simplification seem to be the exception rather than the rule, perhaps because they require the talents of unusually persistent and politically adroit health professionals who are successful in tailoring their efforts to unique local circumstances and opportunities. One community's innovative system can seldom be replicated whole cloth in another, and local political conditions and bureaucratic "turf" interests frequently make service integration all but impossible. As a consequence, service coordination is probably a more realistic goal in most communities than service integration. More will be said in chapter 10 about how to promote this coordination.

Intergovernmental Responsibility

In maternal and child health, as in other realms of human service, there is a complex division of responsibility among Federal, State, and local

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authorities for defining and achieving policy objectives. Some functions are currently not performed well at any level of government whereas others are performed simultaneously at all levels—with substantial resulting confusion about who should be doing what. Indeed, it is a challenge of considerable magnitude simply to comprehend what is happening as various Federal programs are implemented at the State and local level.

States differ widely in how their human service structures are organized, the distribution of responsibility across agency lines, their relationships with county and municipal governments, and so on. Even when policy objectives are clearly established by Federal authorities, administrative and bureaucratic factors unique to each State result in widely varying implementation patterns and problems.

Many States now have human service budgets that rival that of the Federal budget in complexity, if not total dollars. State program categories mirror Federal ones, and are in large measure determined by them. Each State has its own programs and matching fund sources to link with Federal monies, making it very difficult to trace Federal dollars as they merge with State and local ones.

A good example of the complexity at the State level is New York, which has prepared a "children's budget" identifying all State social service expenditures directed at the 0–18 age group. This document shows 11 program functions spread across 25 different agencies with a fiscal 1981 budget of almost $5 billion in Federal, State, and local funds (*62*).

All Federal programs must report periodically to Congress on the progress they have made toward legislated goals. At a minimum, this requires data on State compliance, but programs vary greatly in the amount of detail they can provide. In general, programs that operate through formula grants allowing relatively broad State authority and minimal direct Federal management produce the least data on how money is spent and who is served. Project grant programs produce more such information, but seldom show the relationship between the program in question and other State and local efforts.

If it is sometimes difficult to evaluate State implementation of Federal programs, it is not at all hard to describe the views of State and local administrators about the problems they encounter in trying to use Federal funds efficiently. State authorities insist they could do a far better job of delivering health services to pregnant women and children if the Federal Government would limit its role to defining broad health objectives and transmitting funds in a manner giving States maximum discretion over how they should be spent. In the State view, present problems are the result of categorical program regulations, lack of consistency in defining program roles and client eligibility, and excessive Federal paperwork (*63*). The past decade has been especially difficult, moreover, because the Federal Government has been enlarging its goals, paying less, and demanding more.

An equally forceful case is made, however, by many groups who welcome the Federal involvement and wish that Federal control of maternal and child health programs could be increased, not lessened, so that policy objectives can be pursued with more or less equal vigor everywhere in the Nation. Indeed, as the Panel's site visits made clear, it is likely that in some States, an enlargement of State authority and curtailment of opportunities for local communities and consumer groups to deal directly with Federal authorities might well risk limiting access to health care for many poor and minority children and mothers.

There is nothing new, or necessarily unhealthy, about the federalism debate. It has grown acute in the maternal and child health domain, however, partly because of recent fiscal trends and partly because the history of Federal programs relevant to maternal and child health presents an unusually stark contrast between programs like Title V and Medicaid, which offer the States substantial autonomy, and those such as Head Start, the Comprehensive Health Centers, and other project grant programs, which largely bypass State decisionmakers. This contrast is mirrored in every State by two parallel planning processes: one via the State health department focusing on maternal and child health and crippled children's services, the other via the federally mandated health service agencies focusing on federally supported programs.

In the coming decade, conflicting pressures for greater Federal accountabilty and greater State autonomy must be expected to continue. Once again, the virtues of pluralism are matched by its limitations. However, the Panel believes that certain steps can be taken that will better specify national goals, delineate more precisely the role of the States in attaining these goals, and reduce at least some of the burdens presently perceived by State decisionmakers. We return to these and related issues of governance in chapters 10 and 11.

Personnel with Relevant Expertise

Another aspect of the fragmentation problem results from the rapid increase over the past 30 years in the number and types of professionals whose expertise is relevant to the health care of children and pregnant women. Increase in absolute numbers of personnel probably is less significant in this regard than the growth of new specialties and categories of personnel. The growth of new career tracks within and outside medicine has raised the stakes considerably for those who would coordinate efforts across all relevant professions and public service sectors.

Health care for children is by no means the exclusive province of pediatricians. A wide variety of generalists and specialists are caring for youngsters of all ages in private offices, major medical centers, community hospitals and public clinics. There has been a significant growth and diversification within the nursing profession as well, producing many different levels of maternal and child health care skill. Graduates of pediatric and family nurse practitioner programs, for example, can meet about 80 percent of all child health needs, although that does not necessarily mean they can treat 80 percent of all children. The arrival on the scene of such highly trained personnel does, however, raise questions about the appropriate division of labor between them and physicians in primary care settings.

Very significant growth has also occurred in the number and types of professionals in various health-related fields, including mental health, psychology, nutrition, social work, and special education. In the schools, personnel with health-related expertise—such as learning disabilities specialists and counselors—have proliferated. As attention to psychosocial and behavioral problems grows, it is inevitable that these personnel, school nurses, and professionals in the mental health system will share responsibility with physicians for screening, diagnosis, counseling, and treatment. Similarly, as "boundary" services such as case management and advocacy, transportation, and home visiting come to be seen as essential in promoting appropriate patterns of use, social service workers will find that they increasingly overlap in responsibility with health professionals. Within all of the growing health-related professions there is an unmistakable trend toward specialization, adding further complexity.

The past 20 years have also seen a new emphasis develop on the role of paraprofessionals in offering many access-related services for low-income populations. In Denver, for example, demonstrations in home visiting have involved community residents with no medical training (*64*). These visitors ensure that children and parents in need of services are identified, know about the community clinics, and use the clinics appropriately.

On balance, it is certainly good that the Nation now has more health professionals and related personnel, with more diverse skills. However, a strong centrifugal tendency has been created by this trend. New professions create new turf. Especially in the realm of psychosocial and behavioral problems, there has been a proliferation of new diagnostic categories and therapies, sometimes incongruent with one another.

Problems of fragmentation are likely to worsen in times of funding cutbacks as narrowly defined priorities within health, mental health, education, and social service sectors take precedence over cooperative and collaborative efforts across the lines. This tendency is especially unfortunate for children, who most need a broadly based, all-encompassing pattern of care. Consider, for instance, the prevention and treatment of child abuse—a problem that routinely demands the collaboration of professionals in four public service sectors: the courts, protective services, the health care system, and the schools. If any one of these sectors withdraws, declaring child abuse is not its problem, effective action becomes much more difficult.

"Team care" within the primary health system also is a matter of professional collaboration. The need for more such care has been asserted frequently over the past two decades and is asserted again in this report. In some cases, it is already a reality. Within pediatrics, most younger physicians are now opting for group practice arrangements which pool the expertise of colleagues with different specialty interests along with nurse practitioners and other personnel. These are the primary care practice settings most likely to be professionally stimulating and to provide highest quality care. The federally supported Comprehensive Health Care Centers offer an even more ambitious model, where physicians and nurses work side by side with nutritionists, dentists, mental health professionals, social workers, and early childhood educators. However, routine collaboration between diverse professionals remains the exception rather than the rule, and even referral or consultation patterns tend to be very limited. Consequently, the interests of children are not as well or efficiently served as they might be.

Economies of joint effort are likely to occur over time only if training opportunities, organizational structures, financing incentives, and consumer education are designed to promote them. Because the cost of failing to promote joint effort is so great—in terms of both dollars wasted and low quality of care—the Panel believes that high priority should be given to promoting better collaboration among professionals and service sectors in the future. Strategies for advancing toward this end are discussed throughout the report.

* * * * *

This introductory section, although designed to capture and order the principal concerns that emerged from the Panel's contacts with parents, health professionals, researchers and policymakers, is no more than a rudimentary map of the terrain. Readers seeking more detail may wish to consult the sources referenced in the text, and the materials published in volumes II, III, and IV of this report (*65*).

Succeeding chapters of this volume return to the concerns outlined here and attempt to sketch a national strategy for addressing them. These later chapters will examine major components of national health care policy—health protection and promotion efforts, needed services, the delivery system, financing of services, administrative arrangements, manpower planning and research—to see how each can become more effective in meeting the concerns highlighted here.

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SECTION II

HEALTH PROTECTION AND PROMOTION

CHAPTER 2

REDUCING ENVIRONMENTAL RISKS

Hazards in our physical environment—in the air we breathe, the water we drink, the food we eat, the materials we work with, the homes and communities where we live, the cars we drive and the products we use—can profoundly affect the health of our children both before and after they are born. Many of these hazards are the unanticipated and unwelcome byproducts of the industrial and technological revolution which has transformed our lives in the span of a single century. Some have been a source of concern for years, others have only recently been recognized as problems and still more are likely to be identified in the years to come. The 1979 Surgeon General's Report on Health Promotion and Disease Prevention estimated that 20 percent of all mortality in the United States is due to environmental factors. Risks in the physical environment bear especially heavily on infants and children because of their vulnerability as young, developing organisms, their increased sensitivity to certain substances, their small body weight and greater exposure to certain toxicants, and also because exposure to environmental risks may span many decades.

Many of the factors in the environment which threaten health during pregnancy and childhood can be controlled at least to some extent. To realize the importance of this point, one need only recall the major gains which already have been made as a result of public health initiatives over the past century. Improved sanitation, housing, and water supplies have dramatically reduced the incidence of many infectious diseases. Food safety has been greatly improved. Fluoridation has reduced the hazard of dental caries for millions of Americans. These and other public health measures have been major success stories, and also have proven highly cost effective.

However, after a period in the Nation's history when environmental health programs have accomplished much, certain old problems persist for particular subpopulations and some new problems have been created or discovered which affect us all. Many of the old problems are especially vexing because effective preventive strategies are at hand and simply have not been fully implemented.

The new and newly discovered problems, while no less important in their potential consequences, often are more complex in cause and less easily addressed. These problems have been created in large part as byproducts of the Nation's rapid industrial expansion, increased urbanization, and new technologies. Examples include threats to the fetus, the newborn, and the child presented by chemicals in the environment, risks posed by various drugs and food additives, and fertility-related radiation risks in the workplace. The significance of these and similar environmental concerns is unquestioned, but national strategies for combating them are only beginning to emerge.

Issues of environmental risk to children and pregnant women are very complicated and in some regards beyond the scope of the Panel's charge from Congress. In this report we cannot presume to analyze fully all of the many and diverse factors in the physical environment contributing to lifetime disease and disability, or all of the public policies designed to influence these factors. Instead, we are forced to be selective, focusing only on those aspects of the physical environment which (1) are known to be the major direct causes of death and disability among infants, children, and adolescents, or (2) exert a strong influence during pregnancy and childhood which is known or presumed to have major consequences for health later in life. This approach reflects the current profile of demonstrable health risks to children and pregnant women. In some regards it will undoubtedly be superseded, or modified in emphasis, during the coming decade as new risks come to light and new technologies are developed to combat them.

Although children and pregnant women have unique susceptibilities which make it important to consider them separately from the rest of the population, we also acknowledge a certain inevitable artificiality in focusing only on these groups. Most environmental health concerns apply to the entire population, not just its unborn and youngest members. We believe, however, that it is both feasible and highly desirable for the Nation to develop a coherent health policy for mothers and children which includes as one central component a strong emphasis on environmental health. In recent years, public health and environmental protection policies often have tended to evolve separately from maternal and child health policy. This form of fragmentation, which has potentially serious consequences, should be combatted both conceptually and in the organization of health-related programs and policies in the future.

THE MAJOR HEALTH THREATS

Our review of the evidence on environmental hazards to mothers and children suggests that there are four domains of risk which deserve special attention in the coming decade. We make this judgment on the basis of the two criteria mentioned above, and also because we believe that in each of these four domains much can be done with existing knowledge and technology to prevent or mitigate negative health outcomes. Citizens and

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policymakers have an effective and varied repertoire of instruments to apply. The four domains are:

- Accidents of all kinds in infancy, childhood and adolescence, with special emphasis on motor vehicle accidents and those in the home.
- Chemical and radiation risks to the fetus, the infant and the child, with attention to the dangers of toxic wastes, pesticides, lead, and other pollutants, as well as X-rays.
- Hazards posed by drugs and foods, with particular focus on nonprescription drugs, food additives, and substances presenting special risks during pregnancy.
- Problems caused by inadequate or unhealthful water supplies, with attention to the need for wider fluoridation, potable water in all homes, and adequate sanitation.

These topics are analyzed in the sections which follow.

Several general points emerged in Panel discussion of health protection strategies which cut across all of what follows. These we mention at the outset:

(1) The evidence suggests that many kinds of injuries and health problems can be more economically and more effectively reduced by changing environments than by trying to change behavior directly. Often the most effective strategies are those that work automatically, without action on the part of the person being protected (e.g., automatic passenger restraints in cars). This does not imply that education and the sharing of information are unimportant. Strategies for effective change almost always involve educational elements as well as structural changes in the environment. However, in many areas of risk reduction, education alone is not sufficient to bring about desired results. As one expert consultant to the Panel wryly observed, it does no good to enjoin citizens to jog if the only place they can run is on a city street right behind a diesel bus.

(2) Strategies for health protection should not be automatically equated with regulatory action. Although some of the most effective policies to reduce environmental risk have involved regulation, many other approaches involving both private and public effort and collaboration have shown positive results. Indeed, few serious hazards admit of purely regulatory solutions. Most are more complicated, requiring multiple strategies and the work of diverse groups to overcome them.

(3) Cost-benefit reasoning has become a central component in all policy analysis relating to environmental risks. The Panel recognizes the need for such analysis, but the cost-benefit factors frequently considered in evaluations of proposed or actual interventions to reduce environmental risks must place adequate value on the quality—as well as the economics—of life and health. This is especially true for interventions affecting children. Otherwise cost-benefit analysis presents in the guise of rationality an essentially irrational approach to public policy.

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(4) One important contribution which policymakers can make is to provide citizens the information and the means to assess for themselves the magnitude of environmental risks. This theme is also expressed in the chapters which follow on improving nutrition and other health-related behavior. Much confusion exists at present, resulting in predictable anxieties among parents and other citizens, because it is hard to know what is truly harmful and what is not, and to calculate personal risk in the context of myriad daily activities. While policymakers should not be expected to offer a fine-grained analysis of comparative risks—an undertaking which would prove impossibly complicated in any event—they should routinely provide clear statements enabling parents to understand the general magnitude of risks and the probability of negative health outcomes.

(5) Because risk is inherent in all human activity, and learning to cope with risk is a very important part of growing up, it is simplistic and unwise to fashion policies which are designed only to insulate young people from hazards. Instead, children and adolescents must learn, in developmentally appropriate ways, how to manage risks in their own lives and make prudent choices. Introducing children to sensible patterns of decisionmaking is a challenge to parents, teachers, health care providers and many others who influence the thinking of young people. It is also a challenge to all those who structure the environments in which children live and play.

(6) Finally, if Federal policy is to continue to play an important role in protecting the health of children and pregnant women, various Federal agencies will need to strengthen considerably their coordination with one another over the coming decade. Health protection responsibilities are assigned to numerous units within the Department of Health and Human Services (DHHS), including the Food and Drug Administration, Centers for Disease Control, National Institute for Occupational Safety and Health, National Institute of Environmental Health Sciences, National Cancer Institute, and National Institute of Child Health and Human Development. Beyond DHHS there exist many relevant regulatory and research efforts at the Environmental Protection Agency, the Department of Labor's Occupational Safety and Health Administration, the Consumer Product Safety Commission, the Department of Transportation's National Highway Traffic Safety Administration, the Department of Transportation's Bureau of Alcohol, Tobacco and Firearms, the Federal Trade Commission, and the Department of Agriculture's Food Quality and Safety Service. One reason the Nation still lacks a cohesive policy for the health protection of children and pregnant women is the complexity inherent in trying to understand and coordinate efforts across these disparate entities. In recent years, however, there have been encouraging indications that such coordination is possible and is sought increasingly by the agencies themselves. Various interagency policies are men-

tioned in the sections which follow. These deserve to be reinforced and further developed in the coming decade.

ACCIDENT PREVENTION

Accidents of all kinds are the greatest single cause of death and disability among children. Accidents alone account for approximately 40 percent of all deaths among those 1–4 years old, and 50 percent among children and youth 5–14. Motor vehicle accidents cause a major proportion of these fatalities, while the rest are attributable to such factors as burns, falls and drownings, which usually take place in the home or neighborhood.

Although fatal accident rates for children have declined over the past 50 years, these rates have not decreased as significantly as those for other causes of childhood mortality. In the case of motor vehicle deaths, the rates have decreased only somewhat for children under 14 and have increased significantly for older teenagers. Serious infectious diseases have been combatted much more effectively during the same period, with the result that they have become less important, and accidents more important, as factors in the overall profile of child health risk. When motor vehicle and other accidents are combined, the United States is second only to Canada among 10 Western industrialized nations in its rate of accidental deaths among children. Before the Nation can again experience a significant decline in childhood mortality, renewed efforts must be made to define and carry out effective accident prevention policies.

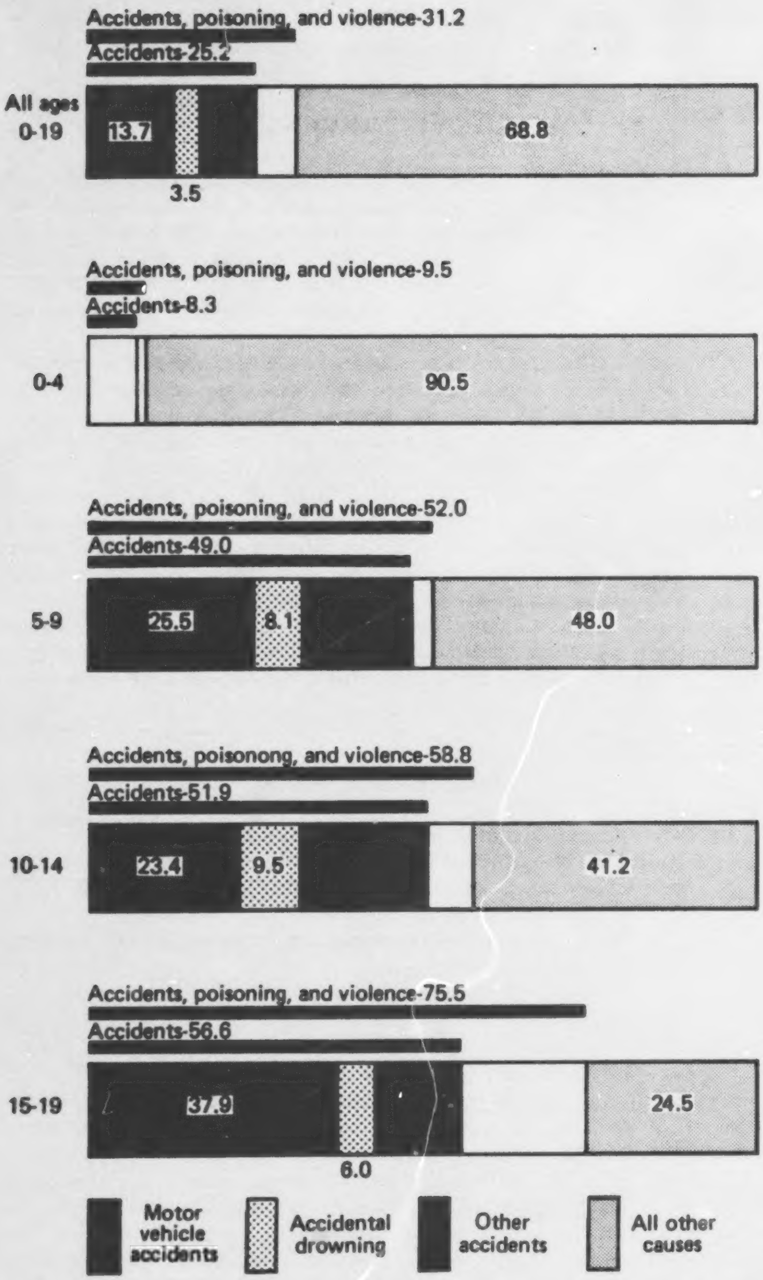
Motor Vehicle Safety

The facts about child motor vehicle accidents are grim indeed:

- Fully one-fifth of all child deaths can be attributed to automobile accidents each year, including the deaths of more than 1,000 children who are under age 5.
- More than 46,000 1–4-year-olds are seriously injured in auto accidents each year (*1*).
- Motor vehicle accidents account for over half the total serious accidents experienced by children.
- Teenagers have the highest motor vehicle death rate of any group, accounting for 20 percent of all motor vehicle deaths in 1978 (*2*).

Such statistics, if reported from some distant battlefield, would make the country sit up and take notice. It is shocking that they reflect routine realities on American highways.

Various strategies for reducing auto fatalitites clearly could make a difference if fully implemented. Use of seat belts and car seats has received particular attention because appropriate use could cut in half the likelihood of death or serious injury in an accident. Yet fewer than one in five drivers presently uses a seat belt, and more than 90 percent of children under age 10 are unrestrained when traveling in cars. Even when parent



Percent of death of children and youths under 20 years of age due to accidents, poisonings, and violence: United States, 1975

drivers are using their own seat belts, more than 75 percent of children are not restrained (*3*).

Passenger safety systems are as important for infants and very young children as they are for older children. In a recent public service advertisement, the General Motors Corporation reminded parents that in a 30-mph collision, a 10-pound child can exert a 300-pound force against the parent's grip, making it almost impossible to hold the child safely on a lap even if the parent is wearing a seat belt. When traveling unrestrained, infants or young children are often killed in accidents that adult passengers survive.

Recent campaigns to educate the public about the importance of child restraint systems and to increase their use have been initiated not only by auto manufacturers and traffic safety authorities, but also by health care providers. The American Academy of Pediatrics has launched a major accident prevention campaign urging all general pediatricians to recommend car seats at a prenatal visit, promote safety belt use by pregnant women, include counseling about infant and child car safety seats in office visits, furnish parents with a list of approved car seats, and establish "loan-a-seat" and seat recycling programs (*4*). These and other educational efforts are positive steps, which gradually should create an improved climate of public awareness. In addition, the Panel believes there would be value in periodic bumper sticker campaigns to remind parents of the need to use child passenger restraints.

In the long run, however, it is probable that motor vehicle injuries will be reduced most effectively by changing the characteristics of motor vehicles themselves. One good way to do this is to require that all new passenger vehicles be manufactured with passive restraint systems—automatic seat belts or air bags—and also incorporate other structural design features which reduce the chances of death or injury on impact. The Insurance Institute for Highway Safety has estimated, for example, that nearly 39,000 persons who died on the Nation's highways between 1975 and 1978 might have lived had vehicles been equipped with air bags (*5*).

Federal Initiatives

The Panel notes with enthusiasm two recent Federal policy initiatives which could substantially increase the safety of autos for all citizens, children and pregnant women among them, over the coming decade. These are the rulings by the Secretary of Transportation that all new cars must be equipped by 1983 with devices automatically protecting front-seat passengers, and the development by the National Highway Traffic Safety Administration (NHTSA) of prototype vehicles incorporating innovative safety technology. Timely implementation of the Secretary's ruling deserves very high priority, as does further development of safety standards governing auto engineering and interior design based on the NHTSA prototypes.

In addition to these initiatives, we believe the unique vulnerability of infants and children requires that NHTSA and the auto industry intensify their efforts to develop special performance standards for child passenger safety. This effort should involve a review of vehicle interior design with particular attention to dangers for children. It also should involve a review of automatic restraint systems to determine their effectiveness for infants and young children and, if necessary, the design and requirement of special systems of automatic restraint for these groups. One important step in the right direction was the 1979 NHTSA standard requiring that child car seats meet certain structural criteria and that instructions on their use be permanently posted on the restraints themselves (*6*).

State Action

Because many aspects of highway safety are the responsibility of the Nation's States and localities, it would be misleading to equate highway safety policy with Federal policy alone. Several States have adopted or are considering new laws requiring that infants and young children be placed in car seats or other safety devices while traveling in motor vehicles. Tennessee adopted such a law in 1977, defining as a misdemeanor the failure to use an appropriate restraint with any child under 4 years of age (*7*). Implementation of the law has been combined with a major public information campaign. Effects have yet to be fully evaluated, but the new legislation is known to have resulted in increased car seat use. Reductions in child mortality may not be as great as hoped, however, because Tennessee continues to permit infants and young children in autos to be held in the arms of an adult (*8*).

The Tennessee law is an example of a wide range of innovative policies for child motor vehicle safety which should be promoted by the States. At present, a modest component of NHTSA grants to the States is set aside for occupant protection programs. This percentage could be increased, and some part of it earmarked for innovative child safety programs. One typical problem which might be addressed by State demonstration projects is the need for improved safety systems in school buses and other conveyances for groups of children.

Other policies involving close Federal-State collaboration can have a very positive, though indirect, effect in reducing child auto deaths and injuries. One is simply to maintain and enforce the national 55-mph speed limit. A significant reduction in traffic fatalities was observed after the new speed limit was adopted in 1974 (from 54,052 in 1973 to 44,525 in 1975). However, traffic deaths are climbing again (to 51,083 in 1979) as enforcement has lapsed in some States. Safety benefits justify continuance of the 55-mph limit regardless of whether energy savings prove consequential in the long run.

Highway design modifications also can help reduce both the number and the severity of accidents. More than a third of all motor vehicle deaths and severe injuries occur when vehicles leave the road and strike rigid objects—trees, utility poles, bridge abutments, and the like (*8*). Removal of such objects where possible, modification of others to break or yield on impact, and the placement of energy-absorbing materials between such objects and the road could significantly reduce the toll of highway accidents. Similarly, traffic safety features can be built into plans for the redevelopment of urban streets and recreation areas, where child pedestrian deaths are most likely to occur.

Another obvious way to reduce risk is by individual decisions among parents to travel by public transportation and have child and adolescent family members do likewise. In 1978, 90 people died in commercial buses, while 28,000 were killed in passenger cars (*2*).

Two-Wheel Motor Vehicles

Motorcycles, while used by a smaller group of young drivers, are a much more dangerous mode of transportation than cars. Because for some youths the motorcycle is not only a means of transportation but a symbol of freedom—and at times rebellion—the high risks involved seldom act as a serious deterrent to use. According to the Motorcycle Safety Foundation, helmets are one effective means of reducing fatalities and serious injuries resulting from motorcycle accidents (*9*). Not all States have mandatory helmet-use laws, however, and in States without them, helmets are worn only about 50 percent of the time.

Since 1976, 27 States have repealed or weakened their helmet use laws. In the same period, motorcycle fatalities have increased by nearly 48 percent even though new motorcycle registrations have increased by less than 1 percent. Two to four times as many head injuries are sustained by unhelmeted cyclists as by those wearing helmets. Many of these injuries require extensive medical care and some involve long-term disability. We believe the high public cost of motorcycle injuries should make helmet safety more than a matter of individual choice.

The risks of mopeds and minibikes also can be considerable, not only to the operators but to auto drivers who may not expect to find such vehicles in the streets. The use of mopeds and minibikes is relatively new in the United States. Mopeds were rare prior to 1975 but it is now estimated that more than 550,000 are being used (*10*). Data on moped accidents show that in 1979 these vehicles accounted for 3,780 injuries to children under age 15. Moreover, two-thirds of moped operators involved in accidents in this country were under age 25 (*11*).

Although the Department of Transportation regulates the construction of mopeds, no Federal authority regulates the construction or use of minibikes. It is commonly thought that these vehicles are intended for use "off the road." Yet, the minibike is capable of traveling up to 50 mph and is constructed in such a way that a 4-year-old child can operate it. Anyone can purchase or ride a minibike, and they frequently are stocked by local toy departments.

It seems only reasonable, if mopeds and minibikes are in fact used on the roads, that operators be licensed by the States and be required to wear helmets. Because reporting procedures so often confuse mopeds and minibikes with motorcycles and bicycles, definitions also need to be clarified so that accurate accident and injury data can be collected.

Alcohol Use

Finally, it is well known that the greatest individual risk factor for fatal car accidents is alcohol use. This is a problem for all ages, but of special concern with adolescent drivers. Drivers 18 years of age and younger were involved in 7,862 fatal vehicle accidents in 1979, and it is estimated that alcohol was a factor in more than half (*12*). Although the Panel does not wish to recommend that the age of licensure for motor vehicle operators be raised to 18, it is worth noting that this step alone would have a major impact in reducing serious accidents. More equitable, we believe, are policies which improve driver education and impose strict penalties for drunk driving among teenagers, such as the mandatory revocation of licenses and mandatory attendance in group or individual counseling programs for youthful first offenders.

In summary, *the Panel strongly recommends that parents, schools, corporate and labor leaders, health care personnel, private voluntary organizations and public policymakers work independently and collaboratively to bring about a major improvement in motor vehicle safety for children and pregnant women.* An adequate national policy will have many elements, including as an absolute minimum the following:

- Health care providers, community-based volunteer organizations, automobile dealers and insurance companies should encourage the use of automobile restraint systems for children from early infancy on.
- Manufacturers should make further efforts to develop inexpensive and effective child restraint systems for infants and small children, and such systems should routinely be available from auto dealers as an option for new car buyers.
- The National Highway Traffic Safety Administration should take three steps to strengthen child motor vehicle safety: (a) resist further delay in the deadline for equipping all new cars with passive restraints that automatically protect front seat passengers; (b) unless auto manufacturers act within the next 5 years to take appropriate action voluntarily, proceed with mandatory standards for incorporating proven safety technology into vehicle designs, including the engineering features demonstrated in NHTSA prototype automobiles; and (c) intensify efforts in the coming 5 years to arrive at adequate special performance standards for child passenger safety.
- State authorities should take the following steps: (a) review carefully the results of recent experience in States with laws mandating use of child restraints, and adopt similar laws if positive effects are demonstrated; (b) require by law that car rental and leasing agencies routinely make child car seats available to their customers without extra charge; (c) support and vigorously enforce the national 55-mph speed limit; (d) enact and enforce mandatory helmet-use laws for motorcyclists and require licensing and helmet use for moped and minibike operators, and (e) initiate major publicly financed bumper sticker campaigns and other media campaigns to alert parents to the importance of child passenger restraints in automobiles.

Home and Neighborhood Safety

At hearings in Denver, Atlanta, and Washington, D.C., the Panel heard testimony urging special attention to the implications which home and neighborhood environments may have for child safety and healthy child development. The homes and neighborhoods where families live are not always designed with children in mind, and may be hazardous to them. One reflection of this is the number of accidental injuries and deaths in the home and neighborhood from burns, falls, drownings, poisonings, firearms, and other sources. These account for approximately 11,000 deaths among children and teenagers each year, roughly as many as die in motor vehicle accidents.

Home and neighborhood safety can only be improved by a strategy combining regulatory policies, new incentives for home builders and product manufacturers, community action programs, and education aimed at better informing parents and children about sources of risk.

Home Accidents

Half of all childhood injuries occur in the home—from fires, scalds, falls, poisonings, and unsafe or improperly used products. Although such accidents result from a combination of environmental and behavioral factors, some of the most effective strategies for reducing home accidents are those that change the structural characteristics of dwelling units and create safer products.

Because burns from fires are such a serious factor in childhood death and injury, accounting for 10 percent of accidental deaths among youngsters 0–14 years of age (*13*), special attention must be given to designing, building, and refurbishing homes to reduce the likelihood of fires. The use of less flammable construction materials, the provision of adequate evacuation routes, the elimination of open gas heaters and the use of automatic thermostats on hot water heaters to prevent excessive water temperatures can all be helpful. The upgrading of local building codes, incentives from the insurance industry and voluntary efforts by manufacturers—such as the recent establishment of protective standards by water heater manufacturers—can reduce the likelihood of fires or scalding accidents in the home. Another approach of well-established value is the requirement that smoke and fire detectors be installed in all residential units, a step that has already been taken in a number of communities around the Nation.

Tap water scalds are a particularly serious problem for very young children. An estimated 5,400 injuries from tap water scalds were treated in hospital emergency rooms in 1979, and almost one-third of these injuries were to children age 2 and younger (*14*). Recent voluntary standards established by water heater manufacturers, prompted by concern from the Consumer Product Safety Commission, give reason for optimism that new hot water systems will not permit excessive temperatures. This experiment should be monitored closely and its effectiveness assessed.

Another initiative worthy of note, this one educational, is the media campaign of the National Fire Administration which teaches children fire safety via television programs such as Sesame Street and by programs in schools (*15*). This campaign is intended in part to discourage juvenile fire setting, which may begin as play or mischief and end in tragedy.

Many sensible policies regarding new home construction are more difficult or costly to implement for existing homes, especially when housing is substandard. Therefore, it is not surprising that disproportionate numbers of low-income children are involved in home accidents, since they are most likely to live in old and substandard housing in central cities and rural areas. Although it is not realistic in the short term to contemplate replacement of all substandard homes, much can be done to improve the safety of existing structures and to educate parents and child caretakers regarding elements of risk. Community efforts to reduce safety hazards, when fully implemented, have shown considerable success. A burn prevention project initiated by the Centers for Disease Control in six counties of Missouri resulted in a 43 percent reduction in fire deaths during a 3-year period (*16*). Likewise, when New York City amended its health code to require window guards in all apartments where young children reside, a significant reduction in falls from windows resulted (*17*).

Asbestos

Another major health hazard in many communities stems from the widespread presence of asbestos in homes, schools, and day care centers, as well as roads, driveways, and playgrounds. Exposure to asbestos increases the risk of developing lung, stomach, esophageal, and colon cancer, as well as asbesteosis, a crippling lung disease. Recently, special attention has been directed at indoor exposure to asbestos, which was used in the construction of many homes, schools, and other buildings from the mid-1940's until the early 1970's. The Environmental Protection Agency banned its use in fireproofing in 1973, and in pipe insulation in 1975. However, ventilation and heating systems of many older buildings circulate the asbestos fibers which pass into the air from ceilings and walls. It is estimated that an asbestos problem exists in some 10–15 percent of the Nation's 100,000 schools, and a number of Federal agencies are currently engaged in an interagency initiative to clarify the extent of the threat and to diminish it. This initiative needs to be broadened to include hospitals, day care centers, and other structures used by children.

Among other potentially dangerous building materials, lead-based paint remains a problem in many older buildings, and is discussed below.

Household Products

The Consumer Product Safety Commission estimates there are about 10 million product-related accidents each year, some 38 percent of which involve children (*18*). In collaboration with the American Academy of Pediatrics and other groups, the Commission has established a series of standards, some voluntary and some mandatory, governing child product safety. Standards cover improved packaging, testing, and development of protective devices, inspection procedures prior to marketing, information to consumers, and monitoring of products in use.

Commission investigations and rulings have involved such areas as toy construction, flammable sleepware, bicycle and crib design, and electrical equipment. A notable success has been the significant reduction (about 30 percent) in child poisonings that followed the requirement for safety tops on all containers of prescription and over-the-counter drugs. This requirement could be extended to other common household substances such as cleansers and insecticides. Success has also been encountered in the case of crib-related injuries, where design regulations and community information campaigns have resulted in a 44-percent reduction of injuries treated in hospital emergency rooms (*19*).

However, regulatory strategies can only be effective when combined with good judgment by parents and child caretakers. Electrical devices, toys, and household implements can never be rendered fully accident-proof. Parents and child caretakers need to understand the most likely causes of home product accidents so they can make more informed decisions about which products to keep from children's reach and which play activities to discourage. One way to increase parent and child awareness is to involve them directly in home safety inspections and other consciousness-raising activities. Such efforts could be initiated by local agencies and organizations—schools, fire departments, Boy and Girl Scout troops, and others—with a modest but targeted demonstration program of Federal incentive grants. In addition, it has been proposed that a universal symbol of danger be designed specifically to communicate a danger warning to children aged 2 and older (*20*). Such a symbol might be developed under the leadership of Federal preventive health authorities and the Consumer Product Safety Commission, with the involvement of child development specialists, the business community, and the media.

Handguns

One type of "product" found in about 20 percent of American households is responsible for a virtual epidemic of deaths and injuries among children and the youth—the handgun. Too often, the presence of a handgun in the home leads to accidental misuse by children even when adults intend that it be kept solely for sport or self-defense. In 1977, gun accidents were the fifth-ranking cause of accidental death among children under 15.

Firearms—primarily handguns—are the most frequently used weapon for suicide and homicide, both of which are on the increase among young people. Firearms are used four times as often as poison, the next most common method of committing suicide, and firearm suicides have been increasing at a much faster rate than suicides by other means. Homicides account for just over 10 percent of all deaths among adolescents and young adults, although the figure is lower (7 percent) for whites and higher (30 percent) for blacks in this age group. Some 25 percent of the 21,000 Americans who were the victims of homicide in 1977 were aged 15–24, placing that group at greater risk than the rest of the population. The deaths of so many young people represent a tragic waste of human potential.

The homicide rate in the United States is far greater than that of most other industrialized nations. Our 1974 rate of 10.2 homicides per 100,000 people compared with a rate of only 0.9 for France, 1.0 for Great Britain, 1.1 for Sweden, and 1.3 for Japan. Easy access to firearms appears to be a prime contributor to the appalling U.S. murder rate. From 1960 to 1974, handgun sales in this country quadrupled to more than 6 million a year.

During that same period, the homicide rate jumped from 4.7 per 100,000 to 10.2 for the population as a whole, and from 5.9 per 100,000 to 14.2 for young people aged 15–24 (*21*).

Evidence from England and elsewhere shows that prohibiting the possession of handguns dramatically reduces the number of shooting deaths and injuries, especially those unrelated to criminal assaults (*22*). The Panel is aware of fierce political controversy in this country about any form of gun control, and recognizes the strength of the organized firearms lobby. Nonetheless, the stakes for the Nation's children are so high that nothing short of a total ban on the sale of handguns, with exemptions for persons such as police, military personnel, and pistol clubs, seems reasonable. We realize such a ban is not likely to prove politically feasible in the short term. One useful, less controversial step would be to mandate the development of child and youth protection standards relating to gun safety. These standards might be jointly developed by a variety of interest groups, including the National Rifle Association, U.S. Conference of Mayors, gun manufacturers, and others. The effects of such a safety campaign on child and adolescent death rates should be carefully assessed. Failure to reduce the incidence of youthful handgun deaths by more than half should be regarded as further impetus for an overall ban.

To summarize, the Panel recommends that *public authorities, corporate and labor leaders, professional organizations, private voluntary organizations, schools, and parents develop and promote broad policies of home and community accident prevention for children.* Specific actions should include at least the following:

- All local governments should upgrade housing and building codes to ensure that dwellings are constructed with less flammable materials, complete fire or smoke detection systems, adequate evacuation routes, no open gas heaters, and hot water heaters with automatic thermostats preventing excessive temperatures. Furthermore, State governments (through insurance commissioners) and the Federal Government should provide incentives for such structural home safety features.
- Current Federal interagency efforts to reduce child exposure to asbestos in homes and schools should be fully implemented, and broadened to include hospitals, day care centers, playgrounds, and other structures used by children.
- The Consumer Product Safety Commission should develop a policy requiring child-proof caps on all common toxic household substances, such as cleansers, insecticides, and the like.
- Local and State governments, businesses, professional, civic, and religious groups should develop community campaigns to raise the consciousness of parents and children about accident prevention and to provide specific information on how to minimize childhood accidents. Such campaigns should promote the direct involvement of children in safety inspections and other activities sponsored by local agencies, including fire and health departments.
- The Department of Health and Human Services should promote the development and dissemination of a universal symbol of

danger that can be recognized and understood by children age 2 and older.

- Congress should enact legislation banning the manufacture and sale of handguns, with exemptions for police, military personnel, and pistol clubs. Until such legislation is passed, Congress should mandate the development and aggressive dissemination of child and adolescent protection standards for gun safety, with particular attention to prevention of accidents and misuse among children and teenagers.

Recreational Opportunities and Sport Safety

Communities must not only help to create physical conditions that will reduce injury and waste of human life, but also structure opportunities for children and youth to engage relatively safely in various forms of recreation and exploration which are a natural part of learning and development. Much of life requires informed risk-taking, and many types of physical play and experimentation among young people are essential. (More is said about this topic in chapter 3.)

Recreation, in the form of organized athletics and individual sport, is a domain where physical risk is often instructive if assumed under controlled circumstances. Problems arise when appropriate opportunities for physical activity are not available, and youthful energies are directed into areas where misjudgment may result in serious injury or adverse consequences for others. Problems can also develop from sport activities when young people are not taught safety measures and ways to prevent injuries as a part of their training.

Urban children and youth experience particular difficulties in finding adequate recreational facilities and opportunities at reasonable cost. Rapid urbanization, haphazard city planning, and short-sighted civic policies have in some cases turned urban environments into areas of unrelenting steel, cement, and glass without adequate public parks, playgrounds, gymnasiums, pools, or playing fields. Even where such facilities are available they often are cramped, a factor which itself contributes to accidents. In football, a high percentage of accidents could be prevented by establishing an obstacle-free zone around the playing field. Appropriate design and use of safety equipment for contact sports also is important, and well worth the modest public expenditure required.

Water sports are a significant factor in child accidents each year. Many drowning deaths could be averted by better community rules regarding swimming pools and boat use, and by more drown-proofing programs. Many youthful drowning victims are intoxicated at time of death, linking this type of accident, like so many others, to substance abuse.

In general, the Panel recommends that provision of adequate recreational facilities, space, and programs be seen as an integral part of a broad national accident prevention strategy. *Recreational facilities, space, and programs should be designed to promote appropriate exercise for all children and youth, and to minimize accidental injuries.*

- Urban planners and architects should routinely be required to consider the impact on child recreational opportunities of new urban construction. Recreational impact on children and youth should become an element of all environmental impact statements for construction in urban areas.
- Boards of education should consider physical education and recreational opportunities as essential components of schooling, and should work with local governments and parents to ensure adequate recreational space and activities for school-age children both in and out of school.
- Organized sports activities for children and youth should be properly supervised, protective equipment should be used appropriately, and young people should be taught sports safety measures as part of their training.
- Greater attention and financial support should be given to the development of improved safety equipment for all contact sports.
- Swimming and water survival classes should be expanded, and State laws and local ordinances should be strengthened regarding the safe use of swimming pools and boats.

Toward a Federal and State Accident Prevention Strategy

Numerous Federal agencies have authority over some part of home and neighborhood accident control, but the Centers for Disease Control candidly state that injuries apart from those related to consumer products are not being addressed effectively at present by any agency of the Federal Government (*23*). This lack of Federal leadership is reflected in turn in States and localities, where health and environmental protection agencies are making only limited efforts to develop accident prevention strategies. State and local health departments, which have traditionally been responsible for accident prevention, have lost resources and are presently attempting to redefine their missions. The Association of State and Territorial Health Officers reports that in 1979, only nine State health agencies had identifiable programs directed at controlling accidents, injuries, and poisonings. Such programs consistently involved less than 1 percent of the total agency budgets (*24*).

A broad Federal child accident prevention strategy should be developed by maternal and child health authorities within the Department of Health and Human Services, acting in concert with other areas of the Department and other relevant Federal agencies, with regional, State, and local authorities, and with parents. This strategy should be designed so that a wide range of Federal programs and policies incorporate an emphasis on child accident prevention. Requirements for full implementation of the new strategy are:

- The establishment, nationally and within each State or region, of a sophisticated and policy-oriented epidemiological data base on accidents, injuries, and poisonings, to aid in targeting resources and programs.

- An increase in the capacity of centralized accident and poison control centers to provide prompt and accurate information to parents and health personnel, through the establishment of a computerized information network and other appropriate strategies.
- Incorporation of accident prevention as an objective of Emergency Medical Care networks. New resources should be provided by Congress for such efforts under this legislation.
- Careful assessment of the effectiveness of the accident control demonstration projects recently established by the Bureau of Community Health Services, and a congressional charge to the Secretary of Health and Human Services to expand to other sites and regions those components of the demonstrations which prove effective.
- The inclusion of accident prevention activities as an integral part of all primary health care programs supported with Federal funds.

CHEMICALS AND RADIATION

Among the most worrisome, pervasive, and complex environmental health hazards are the numerous chemicals and sources of radiation to which Americans are exposed. Such exposure can take place at home, at work, in the neighborhood—even in the hospital. Hazards can arise in the manufacture, formulation, use, transportation, and disposal of toxic chemicals; in the manufacture and application of pesticides; in the administration of drugs and radiation in medical care; in the preservation and coloring of food; and in myriad other ways we may not even recognize.

Toxic chemicals and radiation pose special dangers to pregnant women and to children. Exposure during pregnancy can result in spontaneous abortions, stillbirths, birth defects, and genetic defects. More than 20 agents are known to be associated with human birth defects, and many times that number cause birth defects in laboratory animals (*21*). Young children can suffer growth retardation, reduced immunological response, minimal brain damage, and leukemia as well as acute health effects such as poisoning, diarrhea, and convulsions as a result of exposure to some chemicals. The reproductive capacity of both men and women can be affected by exposure to certain agents, and the effects of such exposure can be transmitted to future generations if the mutation of egg or sperm cells is caused in either parent.

Environmental agents contribute directly or indirectly to virtually all of the major chronic diseases which plague modern American society. Childhood exposure to such agents can be a significant determinant of adult health status because it takes at least 20 years for the full effects of many compounds to become apparent. Cancer is the most dreaded and widely publicized of the chronic diseases which may be caused largely by environmental factors. The National Cancer Institute currently lists at least 20 chemicals and compounds for which there is epidemiological evidence of human cancer causation; among them are asbestos, benzene, vinyl chloride, and arsenic. More than 2,300 specific chemicals are suspected carcinogens. Other major health problems in which environmental agents have been implicated include arteriosclerosis, heart disease, hypertension, emphysema, chronic bronchitis, kidney disease, liver disease, diabetes, anemia, neurologic and behavioral disorders, and immunologic diseases (*21*).

More than 60,000 chemical compounds are commercially produced, with about 1,000 new ones introduced each year. As their use in industry and farming has expanded, these chemicals have made their way into our food and water supplies. Several aspects of their use and disposal merit special concern.

Chemical Wastes

For years now, toxic chemical wastes have been dumped into the Nation's lakes and rivers or buried in community disposal sites with little if any regulatory supervision. The Environmental Protection Agency (EPA) estimates that 90 percent of the Nation's hazardous wastes are still being disposed of by environmentally unsound methods (*25*), despite the enormous public concern stirred by the discovery that chemical leakage from the Love Canal disposal site in New York State was exposing nearby residents to major health risks. Significantly, one of the first indicators that something was amiss at Love Canal came from the higher than normal number of spontaneous abortions recorded among pregnant women in the area. An association with congenital abnormalities is also suspected. One lesson is that the consequences of improper toxic waste disposal may be gravest for the unborn and the young. Another is that improved perinatal epidemiology and surveillance can become a major public health tool for those monitoring chemical risks.

The EPA has identified some 30,000 waste disposal areas in the Nation as presenting potential health problems. Of the 645 sites it has investigated thus far, the agency has found more than 100 which it says pose a serious threat to approximately 600,000 citizens (*26*).

EPA has recently been granted regulatory authority over new toxic waste disposal sites and has set standards requiring all those dumping waste into the environment to keep records on precisely what is being dumped and where. But thus far there has been no adequate action to reduce dump site hazards because the EPA has no funds for this purpose and the focus of its regulatory authority is on new sites rather than old ones. Cleanup of old dump sites and monitoring of all such sites is essential. Alternative methods of disposal also should be studied for the future, including incineration of waste, resource recovery, and recycling.

Pesticides

Pesticides can pose a health hazard to workers engaged in the manufacture and application of such substances, to families who live near or work in sprayed areas, and to consumers who eat foods containing pesticide residues. The insecticide Kepone, for instance, not only caused serious neurologic and reproductive effects in workers at the Virginia plant where it was manufactured but also contaminated countless thousands of fish as it spread, after discharge from the factory, in unknown quantities along the James River, Chesapeake Bay, and Atlantic Ocean.

The accumulation of certain chemicals in tissues means that exposure to very small amounts over sufficient time can result in the buildup of toxic doses. A number of fat-soluble pesticide chemicals have been banned from use by the EPA, such as DDT, Aldrin, and Dieldrin. Nevertheless, these chemicals remain in the environment from past use and human exposure occurs in foods and drinking water. Studies of the breast milk of nursing mothers have revealed that the majority have one or more of the chlorinated hydrocarbons in detectable amounts in their milk. Thus, the fetus may be exposed by passage across the placenta, and the newborn begins life with the high likelihood that such chemicals are in its diet either in breast milk or other foods.

Aerial spraying of pesticides constitutes a special problem since the wind can carry such chemicals to nearby homes and schools, thus greatly increasing the number of people exposed to them.

Considerable anecdotal evidence was presented to the Panel by health authorities during the Panel's site visit to rural Mississippi that child illness is higher in areas of intensive aerial crop spraying, and these same authorities also suspected that some proportion of birth defects, stillbirths and infant mortality could be attributed to pesticide exposure in areas of the Delta region where 2,4,5–T is still used on rice crops.

Because it can take many years to determine the full health effects of any compound, and because longitudinal studies are expensive and sometimes inconclusive about causation, complete knowledge of long-term health risks from pesticides is not likely soon. But the fact that partial evidence is often the only evidence we have is not sufficient reason for inactivity. The burden of proof that damage will not result from commercially available sprays and other insecticides should rest with manufacturers and policymakers rather than with parents.

Pesticide tolerances presently are calculated using consumption data and average body weight of an adult. Because children have a smaller body weight, the amount of pesticide which can safely be ingested by a child may be different than for an adult. Food consumption patterns also differ for children resulting in a special profile of risk. These and other factors unique to the child population deserve sustained attention from manufacturers, public health officials, environmental protection authorities, and researchers.

Lead

Some urban children are at special risk for high levels of lead in the blood because lead in the air exerts a combined effect with lead in drinking water, and sometimes with ingested lead paint chips. Elevated blood lead levels are now known to have a serious negative effect on health, and indirectly on health-related behavior such as school performance (*27*).

More than three-quarters of American familes now live in metropolitan areas, and in most of these areas toxic gases and particulates, mostly from automobiles and industries, pollute the atmosphere. Lead is a major problem along with excessive sulfur oxide, carbon monoxide, ozone, and nitrogen oxides. Airborne lead, like the other pollutants, may pose more severe problems for children than adults, not only because children will experience them over a longer period but because many particulates are densest close to the ground, where children are exposed more intensively. Although the Environmental Protection Agency has issued regulations for stationary sources, such as smelters, it has not yet dealt with the problems surrounding motor vehicle emissions. In particular, the phase-down of lead in "leaded" gasoline has not been adequately carried out.

Lead which enters drinking water from old pipes or the solder used to join copper tubing presents an equally pervasive problem. Most of the Nation's older cities have not yet faced the enormous and costly task of modernizing and rendering safe their water systems. Similarly, the pipes found in older housing may pose significant risks.

One of the most difficult and serious problems to combat is lead-based paint. Unlike air and water borne lead, lead in paint is uniquely hazardous to young children. It is sometimes ingested by children in the form of paint and plaster chips in concentrations sufficient to produce serious impairment. Although the dangers of lead paint have been well publicized and its use is now banned in all new housing, adequate steps still have not been taken to remove it from older homes where children live. It is notable that of the housing stock directly owned or financed by the Federal Department of Housing and Urban Development, 1.8 million dwellings built before 1971 contain lead paint (*28*). Targeted efforts to remove this hazard, at least from rooms and at levels where children can reach it, would seem a minimal Federal responsibility.

Radiation

If exposure levels are high enough, ionizing radiation can cause leukemia and other cancers, genetic defects, and tissue injury. Approximately 45 percent of the radiation to which the general population is exposed comes from medical and dental use of X-rays and from radioactive materials used for diagnosis and treatment. Thus one major point of policy leverage in reducing radiation risks for most Americans is through the regulation and appropriate use of medical and dental X-rays. Almost all remaining radiation exposure is from naturally occurring radioactive materials in water, soil, and air, except for roughly 5 percent from fallout, industrial uses, production of nuclear power, and various consumer products.

The Food and Drug Administration is empowered to regulate medical X-rays. This can be done by establishing standards on X-ray machines themselves, by establishing exposure guidance rules, or both. Thus far only the first approach has been used, although the possibility of issuing patient exposure recommendations is being discussed. Two States—Illinois and Vermont—have developed population exposure limits, and others currently are developing exposure guidance rules. The Panel believes it would be wise to create a national standard of exposure limits for pregnant women and children under 1 year of age, to guard against developmental damage and the risk of leukemia from X-ray exposure. Physicians ordering X-rays should inform parents of potential risks to their children before X-rays are used for diagnostic purposes, and operators of X-ray machines should be required to utilize protective coverings to limit the exposure to a medically necessary minimum. Operators also should display a notice in all X-ray rooms instructing the patient to inform the technician if she has reason to think she might be pregnant.

Occupational Exposures

Among the approximately 105 million American workers, an estimated 73 million are between ages 16–45 (*29*). Many are exposed daily to one or more occupational health hazards: carcinogenic chemicals, pulmonary irritants, radiation, and various causes of psychological stress such as excessive noise. Although no accurate statistics exist regarding how many of the 400,000 new cases of occupation-related disease each year involve persons of childbearing potential or pregnant women, the number is certain to be large. Some hazards have the potential of causing birth defects, genetic changes, stillbirths and spontaneous abortions, as well as causing sterility and reducing fertility.

Most of the serious occupational hazards affect those whose work involves sustained close proximity to toxic agents and radiation. The Surgeon General reports that 34,000 chemicals in the workplace have toxic effects, and over 2,000 are potential human carcinogens. Nine out of ten American industrial workers are not adequately protected against at least 1 of the 163 most common hazardous industrial chemicals. Further, the development of hazard control technology has lagged behind the growth in use of hazardous chemicals and sources of potentially dangerous energy such as lasers, nuclear reactors, ultrasound, and microwaves(*21*).

Occupational hazards may be controlled by altering work environments, requiring special protective equipment, and offering special training. The Occupational Safety and Health Administration is empowered to establish standards for health in the workplace, and the National Institute for Occupational Safety and Health, within the Centers for Disease Control, also performs an important role in sponsoring relevant programs and research. These agencies have begun to develop policies toward reproductive hazards in the workplace, but no comprehensive national policy exists. Such a policy needs to be developed to address those sources of chemical and radiation risk which cause reproductive failure in male and female workers, and genetic damage or congenital anomalies in the fetus and the newborn. Immediate attention should be given to establishing standards for occupational exposure to lead, asbestos, pesticides, and radiation. The policy should be updated at intervals with the accumulation of new knowledge and information regarding occupation-related risks.

Standards which focus only on women of childbearing age can lead to discrimination in the workplace, either by exclusion of women from certain types of jobs where there is chemical exposure, or by requiring evidence of sterilization in women to avoid fetal exposure to chemicals. Chemicals can have adverse effects on males as well, as in the case of the pesticide DBCP which is believed to have caused sterility in male workers, and lead and other substances which can cause mutation of male sperm cells leading to miscarriages and birth anomalies. The workplace should be safe for both sexes, and standards should allow both men and women who want to have children to transfer to another location with no exposure to risk-related chemicals, without financial penalty. This last point is particularly important because higher pay for hazardous jobs may lead some employees to choose short-term financial gain over long-term health protection. Agencies seeking to help vulnerable employee groups should target their efforts on communities where only one industry, with hazardous working conditions, offers the major employment opportunity.

Federal Policy

Because chemicals and radiation pose significant risks to the fetus, the newborn and the young child, certain minimal federal legislative, regulatory, and administrative steps should be taken to address these environmental hazards. Such steps include at least the following:

- Congress should move swiftly to enact legislation and appropriate funds establishing a partnership of private corporations and public authorities to clean up existing chemical dump sites. In implementing this legislation, first priority should be given to sites presenting greatest immediate risk to significant numbers of pregnant women, infants, and young children. The Environmental Protection Agency should further establish a strict monitoring system for future toxic waste disposal, with approporate indicators of risk to pregnant women and young children, under the provisions of P.L. 94–469, the Toxic Substances Control Act of 1976.
- Exposure and ingestion tolerances for pesticides should be calculated to reflect levels considered safe for infants, children, and adults of both sexes, with particular attention to pregnant women. Regulation of pesticides should be based on premarket tests including reproductive studies in test animals.
- Special attention should be given by the EPA to levels of pesticide ingestion for migrant and seasonal farm workers, their families, and other rural families.
- The Department of Health and Human Services should work jointly with the Department of Housing and Urban Development, the Environmental Protection Agency, the Department of Energy,

and other relevant Federal and State agencies to develop a comprehensive national policy for removing dangerous levels of lead from air, water, and paint or other housing materials, with special attention to educating parents and minimizing child exposure.

- The Food and Drug Administration should establish national guidelines of X-ray exposure limits for children and pregnant women. Also, health providers should routinely employ every available means to protect children and pregnant women from unnecessary exposure to X-rays, including formal and informal educational programs for parents and children.
- The Occupational Safety and Health Administration and the National Institute of Occupational Safety and Health should collaborate with other relevant Federal and State agencies and professional organizations such as the American College of Obstetricians and Gynecologists to develop a comprehensive policy regarding reproductive hazards in the workplace.

DRUG AND FOOD SAFETY

Approximately 70,000 prescription drugs and more that 200,000 over-the-counter drugs are now on the market, many of them used by children and pregnant women. Although for the most part these drugs are safe if used appropriately, the chance of adverse reactions is real for many of them. Adverse reactions sometimes are immediate and discernible, but in other instances effects may be more subtle, cumulative or difficult to detect.

On many grounds, safety criteria for drug use among young children and pregnant women must differ from those for other groups. Pregnancy and early childhood present unique susceptibilities, changing hormonal balances, and a series of other biochemical considerations which require special attention and vigilance by parents, drug manufacturers, and regulatory authorities.

The FDA has recently established labeling standards for prescription drugs used during pregnancy so that physicians, pharmacists and consumers will have information about correct use and special risks. Such labels will be attached not only to drugs commonly used during pregnancy such as sex hormones employed in diagnostic testing, oxytocic drugs for inducing labor and anesthetics used during delivery, but also to general-use prescription drugs such as analgesics (e.g., Demerol) and diuretics known to carry special risks during pregnancy. The new labeling regulations will be directed principally to physicians and pharmacists, although labels will be written in language intelligible to the consumer.

One serious limitation of the FDA policy is that it does not apply to nonprescription drugs, many of which pose risks for pregnant women. Negative consequences have been associated with the use of aspirin, antihistamines, sleeping pills and numerous other over-the-counter preparations, causing many obstetricians to discourage any use of these drugs at all during pregnancy. Labeling regulations, requiring warnings in plain

English, need to be developed by the FDA for all over-the-counter drugs with known or presumed risks during pregnancy.

The special sensitivities of pregnant women and children should also be taken into account in research and testing of new drugs. Clinical testing of new pharmaceuticals is generally done on adults while infants and children may have a quite different threshold dosage for safety and efficacy.

A coherent national policy governing drug testing and research to determine safety and efficacy of drugs for infants, children, and pregnant women needs to be developed by the FDA, with criteria for clinical testing, premarketing approval, and subsequent monitoring of effects. Longitudinal research should be included to evaluate both the immediate and long-term effects of drugs used during pregnancy and childbirth on maternal and infant outcomes and subsequent physical, neurological, and behavioral development of offspring. It also is essential that maternal and child health expertise be represented on advisory boards utilized by the FDA to review policy toward all drugs which may affect the health of fetus and the mother, and to develop more rigorous criteria and procedures for review of new drugs intended for use among women and men of childbearing years.

The Food and Drug Administration also performs a vital role by routinely monitoring thousands of different commercially available foodstuffs for nutritional content, use of additives, and unintended presence of toxic substances. This task is potentially so vast that it must be performed selectively, on a sampling basis. One recent successful FDA policy initiative has been the requirement of labels specifying nutritional content on all commercially sold baby foods. As a result of this policy, the nutritional quality of baby foods has improved since both manufacturers and consumers are more aware of nutrient content. The change has occurred without undue cost to industry, and with clear social benefits.

The composition of infant formulas also has been the object of FDA policy, as well as recent Federal legislation. The FDA, working closely with organizations such as the American Academy of Pediatrics Committee on Nutrition, developed regulations on the nutrient composition of infant formulas as early as 1971. These regulations served as guides for the manufacturers and provided information to consumers. New scientific information has required that the regulations be updated. The need for vigilance is demonstrated by recent experience with one commercially available formula whose chloride content was so low as to result in nutritional imbalance among infants fed on it exclusively. Another of the potential problems with certain infant formulas is contamination by toxic chemicals such as lead, which sometimes is introduced due to leaching from the seams of metal containers. Sadly, elements in formulas are not the only hazard to nutrition of the newborn. Contaminants also may be present in human breast milk. PCBs, pesticides and certain chemicals are known to enter breast milk. There are still many unanswered questions about the absorption of such contaminants and their biological influence on the health of the mother and infant. Some epidemiological surveillance has been done to assess levels of exposure of the population, but more is needed. High priority should also be given to more research on the effects of contaminants in human milk.

Additives are pervasive in the foods consumed by mothers and children, and can constitute another source of risk. Certain coal tar derivatives used for coloring have been shown to be carcinogenic in animal tests. Some researchers believe that color dyes also may contribute to hyperactivity in certain children. Because coloring and additives give no nutritional benefit and pose an unknown risk, their use should be subject to research and regulatory scrutiny in the future.

In reviewing the numerous research activities of the FDA and other relevant Federal agencies, *the Panel believes that three research priorities of food safety should be established in addition to, or in reinforcement of, those addressed in the previous paragraphs.* These include the following:

- Further work on nutrient imbalances and toxic exposures in the foods of infants, adolescents, chronically ill children, and pregnant women, with exploration of implications for a more coherent national policy on necessary safeguards.
- New research on communication of safety and nutrition information to consumers, including assessment of how best to reinforce labeling policies so as to improve consumer choices.
- More intensive investigation of relationships between food composition, food additives, and child behavior, with special attention to the effects of nutritional imbalances and additives on school performance, social adaptation, and coping skills.

Alcohol, Nicotine, and Caffeine

Mounting evidence suggests that serious adverse consequences to the fetus and the mother can result from excessive consumption of alcohol, nicotine, and caffeine during pregnancy. Babies born to women who consume excessive amounts of alcohol during pregnancy can suffer central nervous system disorders, growth deficiencies, and other birth defects. Steps are being taken by the Federal Government and relevant professional and consumer groups to educate the public about the dangers of fetal alcohol syndrome, although no regulatory policy has been established to require warning labels or otherwise communicate the dangers of alcohol during pregnancy. Problem drinking in pregnancy is discussed in greater detail in chapter 3.

Babies born to smoking mothers are more likely to be of low birth weight at full term, to be premature, and to have mild deficiencies at birth. An association also exists between the number of cigarettes smoked per day and the probability of spontaneous abortion. As noted earlier in the report, these facts give cause for concern because even though the percentage of women who smoke has declined, the rate of initiation among younger women entering the childbearing years has not. More educational programs are needed aimed at teenagers and women of childbearing years to emphasize the possible adverse effects of smoking on pregnancy outcome.

In animal testing, it also has been established that caffeine can produce birth defects. Although evidence still is not conclusive enough to merit warning labels for caffeine-containing products, the FDA presently plans to warn women that they should stop or minimize drinking of coffee, tea, and colas during pregnancy.

FDA Policies

In summary, *the Panel recommends that, at a minimum, the FDA take the following steps in collaboration with other federal agencies and state and local authorities to further assess and make known potential hazards which drugs and food substances may pose to children and pregnant women:*

- Existing Federal drug labeling requirements pertaining to risks for pregnant women should be extended to nonprescription drugs. The special sensitivities of pregnant women and young children should be taken into account when setting standards and establishing threshold levels for the safety of all drugs and foods.
- The FDA should establish a coherent national policy regarding food dyes and additives as these affect pregnant women, infants, and children, and issue regulations, require warning labels, and take other appropriate steps whenever significant risks are found. When appropriate, the FDA should act in collaboration with the Alcohol, Tobacco and Firearms Agency of the Treasury Department, other government agencies, private industry, and relevant professional groups.

SAFE AND HEALTHY WATER

Most communities in the United States have eliminated obvious sources of infectious disease from their water systems, but three problems remain. Many community water supplies still are not fluoridated, some families still lack adequate potable water and sanitation, and certain potentially dangerous chemicals still are found in drinking water.

Fluoridation

Tooth decay is one of the Nation's most common health problems, affecting 95 percent of all Americans. In 1978, total dental expenditures in the United States reached $13.3 billion, up from $3.7 billion in 1968, and accounted for 7.9 percent of all personal health care expenditures.

Children who from birth have access to fluoridated drinking water average 50–70 percent less tooth decay than those without. Loss of first permanent molars can be reduced by three-quarters, and some types of caries by as much as 95 percent (*30*). One conservative estimate has suggested that water fluoridation, by reducing the incidence of dental caries, produced annual savings of treatment costs of $11 to $16 per capita, resulting in a cost-benefit ratio of roughly 1:50 after 12–15 years

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(*30*). This means that for every dollar spent on water fluoridation, 50 dollars are saved in treatment costs.

In spite of these facts, fewer than 50 percent of all American families and children have access to fluoridated water, and those who do may in some cases be served by fluoride-deficient water systems. Other alternatives are available or can be used in combination with water fluoridation. In areas where fluoridation of community water supplies is not feasible, fluoridation of school water supplies can still provide substantial protection—an estimated 30–40 percent reduction in tooth decay. A variety of other measures can also help, including the use of appropriate toothpastes, fluoride mouth rinses, dietary fluoride supplements, and the direct application of fluoride to the teeth by the dentist or dental auxilliaries. But none is as effective or economical as direct fluoridation of water supplies.

The Federal Government has been less than strenuous in its support of water fluoridation, partly because some groups have argued that fluoride may pose a long-term hazard to health. The recent Surgeon General's Report on Prevention does not lend support to this view, arguing instead that research over the past 35 years has produced no evidence to support concern. Another reason for Federal hesitance has been that decisions to fluoridate remain a local political prerogative. This is appropriate, but need not preclude a supporting Federal role.

The first Federal funds ever provided to assist States and communities in voluntary fluoridation projects, totaling $2 million, were appropriated during 1979. This figure rose to $6.8 million in 1980. The President's 1981 budget supported the importance of fluoridation as part of a total prevention package, and requested additional funds to support voluntary community efforts in the future. The Panel supports these initiatives and believes that the program of Federal startup grants for voluntary fluoridation projects should be continued and enlarged. Educational efforts offer another avenue for Federal support. A recent report from the General Accounting Office indicates there has been a decline in public knowledge about the benefits of fluoridation. This may in part be the result of a tendency to pay greater attention to "new" health hazards than to persistent old ones, but whatever the reason, a renewed effort to inform people of the benefits of fluoridation is warranted.

Potable Water and Sanitation

An examination of 1977 Annual Housing Survey indicates that approximately 1.2 million American children live in households which have sources of water other than public or privately owned municipal systems or individual wells (*31*). Approximately 600,000 live in households into which no water is piped. These figures indicate a substantial number of children are members of households which get their water directly from bodies of water or have their water shipped in and stored. In the first case, the water is probably boiled before use but otherwise not purified. In the latter case, the tank trucks that transport the water and the facilities in which the water is stored are highly susceptible to contamination, as are all closed water systems.

In addition, the same survey estimates that there are approximately 1.35 million children living in homes with incomplete plumbing facilities. These children may contract disease or illness from mere exposure to untreated waste water as well as from ingestion of contaminated water.

The children most likely to live in dwellings like those described are the same high-risk children who are often denied access to health care because of geographic or socioeconomic factors. Typically, they are black or other minority children living in households with incomes of less than $10,000 a year and which are located in rural areas (especially the South) and headed by one parent having only an elementary level education.

The Public Health Service has no concrete data as to either the total number of cases of enteric disease caused by consumption of or exposure to contaminated water, or the number of children afflicted with these diseases as a result of drinking or coming in contact with disease-laden water. However, it did report that there were 31 separate outbreaks of enteric disease emanating from contaminated water sources in 1978. These outbreaks involved approximately 11,000 cases.

A large percentage of these 11,000 cases were apt to be children, because children are generally more susceptible to enteric disease. Young children under the age of 9 are likely to suffer disproportionately. The Public Health Service cautions that prevalence among children may not be greater than for the rest of the population; it may be that more cases are reported because care is sought more often for children manifesting symptoms of these diseases. However, children must receive care more often than adults because they cannot tolerate the acute dehydration which characterizes enteric diseases. The effects of these diseases on children can be severe if proper medical care is not readily available or sought.

Problems of inadequate water and sanitation facilities, which are particularly prominent in the rural South and Southeast, need to be brought to the attention of relevant State Governments, State and local environmental protection authorities, agricultural authorities responsible for rural water projects, and the Public Health Service. In addition, national research is required to ascertain the total number of cases of enteric disease among American children which can be directly attributed to drinking or coming into contact with contaminated water.

Chemical Contaminants

Environmental protection and health authorities also face the problem of removing certain potentially dangerous chemicals found in drinking water. Excessive nitrates, sodium, lead, and organic contaminants may pose hazards to children and pregnant women.

The amount of sodium entering drinking water supplies could be somewhat reduced by the substitution of other compounds for salt commonly used on icy roads in winter. Chloroform, which can affect fetal growth, often forms as a result of a reaction between chlorine and organic contaminants but could be removed by treating drinking water with granular activated carbon. The Environmental Protection Agency is required to establish standards for various pollutants in drinking water. We believe that this mandate should be carried out with special concern for risks to pregnant women, and long-term cumulative risks to children.

Next Steps

Clean and healthful community water supplies should be available to all American families. As immediate and minimal next steps, the Panel recommends that:

- All community water supplies should be fluoridated wherever possible, and Federal assistance to States and communities for water fluoridation should be expanded. Where community water supplies cannot be fluoridated, school water supplies should be, and fluoride toothpaste, mouth rinses, supplements, and topical treatments should be encouraged.
- Problems of inadequate potable water systems and sanitation facilities should be brought to the attention of relevant State and Federal agencies. Collaborative effort of both State and Federal agencies, initiated by the Public Health Service, should result in a specific program to correct these serious health hazards.
- Federal funding should be provided for a national study to ascertain the incidence and prevalence of all infectious diseases among children in the United States which can be attributed to contaminated water supplies, with the subsequent use of the study to target remedial efforts.

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CHAPTER 3

HEALTH AND BEHAVIOR

The relationship between health and behavior is both self-evident and complicated. Everyone knows that health is shaped significantly by individual choices—to eat some things and not others, take risks or avoid them, follow health-related advice or ignore it, exercise or not. But such decisions are made in human contexts with many different economic, social, and psychological elements which complicate and influence them.

Health-relevant behavior is an integral part of overall lifestyle and behavior, which starts forming in infancy. It is influenced by a wide variety of factors including the examples set and instruction given by parents, siblings, peers, schools, religious and community groups, and the media. Behavior may be modified by what is consciously taught, but it will certainly be shaped by what is seen, heard, and felt in the course of daily life.

The health of children and youth is significantly affected by their own behavior and by the behavior of others, particularly their parents and peers. A mother's influence commences even before birth, for a number of maternal behaviors such as smoking, drinking and drug use can affect the outcome of a pregnancy. As children develop, they learn to respond to their environment selectively and in patterns characteristic of their social groupings. These patterns have considerable influence on adaptation, on health, and even on how health is defined. Many behavior patterns which have significant implications for health over a lifetime are formed during childhood and adolescence. Successful attempts to influence health-related behavior in positive ways early in life therefore can have significant long-term payoffs.

Other chapters of the report contain much material relevant to health and behavior. In the final analysis, it is impossible to analyze topics such as environmental risk reduction, improved nutrition, or access to health services without consideration of behavioral factors along with financial, organizational, and other factors. We devote a separate chapter to health and behavior to permit a sustained look at those aspects of behavior which are of particular salience to health in each of four life stages (pregnancy, infancy through the preschool years, elementary school age, and adolescence), and to discuss how five of society's major institutions—health care settings, the schools, the media, the workplace, and the community—can influence health-related behavior through education, guidance, and counseling. These matters are addressed in the sections which follow.

Several caveats recurred in all of the Panel's discussions of health and behavior, and apply generally throughout the chapter. First, the degree of control people have over their health-related behavior is not evenly or randomly distributed in society. Whether children or adults, it is far easier for those with extensive education and high incomes to adopt a healthy lifestyle than it is for individuals at the low end of the socioeconomic spectrum. In addition, there are value judgments and moral questions implicit in many behavioral decisions, and a delicate political and philosophical dilemma is presented whenever public policy seeks to influence private behavior. The emphasis, the Panel believes, should be on promoting informed decisionmaking rather than on behavioral prescription.

Finally, education, counseling, and other efforts to influence individual behavior do not preclude simultaneous moves to restructure environments so as to enable healthful choices to be made. As noted in chapter 2, some of the most useful "behavioral" interventions are those which require no voluntary action by the individual but instead preclude a dangerous choice or permit a healthful one automatically. Also, many of the most successful efforts to promote healthy behavior involve elements of both structural change and education.

It makes no sense to consider policies to enhance health-related behavior among children and pregnant women without first acknowledging the widely differing age groups involved, each with its own developmental stages, profile of behavioral risk, array of socializing influences, and opportunities for learning. Health promotion for women of childbearing age certainly is not the same as health promotion for children and youth, and among young persons it is useful to distinguish among at least three groups—children five and under, elementary school children, and adolescents.

Even these groupings are not differentiated enough for many purposes. From a developmental standpoint, it is clear that special conditions apply in the first six months of life, to 1 to 3 year olds, to preschoolers, to early adolescents, to youngsters 16 to 18, to very young mothers, and to various other age categories (*1*). Economy of presentation requires that we settle here on four groupings, pointing out special behavioral circumstances or issues for subgoups when appropriate. For each age range we review only selected developmental influences and behavioral risk factors. A comprehensive discussion of needed health services for children and pregnant women is found in chapter 5.

PREGNANCY

In the process of child development, the earliest phase and in many regards the most important is fetal development and birth itself. Maternal behavior can influence fetal development and pregnancy outcome in a number of ways, beginning with conception. If the decision to become pregnant is made consciously and a child is wanted, parent attitudes and developmental prospects for the child are more likely to be positive than if conception is inadvertent. Hence responsible sexual behavior itself is a significant factor in reducing developmental risk. Use of family planning counseling is one way to reduce the chance of unwanted pregnancy. Another is widely available education in human sexuality.

Good nutrition both before and after conception, and access to timely prenatal care, are probably the most important factors in promoting normal pregnancy outcomes, as discussed elsewhere in this report. Both are most effective when they include a significant educational and counseling component, informing prospective parents of appropriate behavior during pregnancy. Education and counseling can be provided in many sites, including health care settings, free-standing clinics, the workplace, and even at times the school.

Alcohol, Smoking, and Drug Use

Certain maternal behavior—most notably alcohol consumption, smoking and drug use—can seriously affect pregnancy outcomes and therefore warrants intensive concern. Since such behavior is almost always well-entrenched before a woman becomes pregnant, the most urgent need is to help the pregnant woman understand the risk her behavior poses to her unborn child and to assist her in modifying her behavior in ways that eliminate or reduce those risks.

Heavy drinking by pregnant women has been shown to result in a characteristic set of abnormalities called fetal alcohol syndrome (FAS) which afflicts as many as 4,000 to 5,000 infants a year. These infants are often of low birth weight, mentally retarded, and may exhibit physical, neurological, and behavioral problems, with abnormalities and other serious defects in almost half of the cases. Both the risk and the degree of abnormality go up as consumption of alcohol increases. One Boston City Hospital survey found 74 percent of infants born to women who consumed more than 10 drinks per day had the fetal alcohol syndrome. Congenital defects were found among 32 percent of infants born to heavy drinkers compared to 14 percent of the offspring of moderate drinkers and 9 percent of infants of nondrinkers (*2*). The effects of moderate drinking, or of occasional binge drinking, are less well documented but animal studies suggest caution in the use of even small amounts of alcohol by pregnant women.

There is also substantial evidence that smoking increases the risk of spontaneous abortion, neonatal death and low birth weight. Women who smoke double their risk of having a low birth weight baby. Infants born to smokers weigh an average of 200 grams less than those born to nonsmokers, and this effect is independent of all other factors known to influence birth weight. Analysis of data from several studies in the United States and Canada shows from 20 to 40 percent of the incidence of low birth weight in these countries is attributable to maternal smoking. Other studies indicate that the more cigarettes a woman smokes, the lower the birth weight of her baby. However, if a woman stops smoking during her pregnancy, her risk of delivering a low birth weight baby drops back to that of a nonsmoker. Thus, it is clear that health education efforts which succeed in persuading pregnant women to quit smoking could have a significant effect on infant health (*3*).

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Most health-damaging habits are exceedingly difficult to break once they have become a part of the individual's normal everyday lifestyle, even when the person wants to change. Motivation, however, can make a difference. Studies have shown that a smoker facing an immediate health threat from his or her habit (such as a cardiac patient) is far more likely to quit than someone contemplating the risk of getting cancer 20 years hence. Pregnant women share this heightened motivation to modify their behavior, for nearly all expectant mothers are anxious to avoid harming their unborn babies.

Drug use during pregnancy also can result in serious risks to fetal development. Some of the most dramatic and tragic effects are among infants born to users of illicit and addictive drugs such as heroin. Women of child-bearing age make up about one-fourth of all heroin addicts. In one metropolitan hospital center, there has been a five-fold increase in births to drug addicted women in the past 20 years (*4*). Similar trends probably can be found in other urban areas.

Less pronounced but more widespread problems have resulted from inappropriate use of certain prescription drugs during pregnancy and at the time of delivery, including pain killers and diuretics. Adverse effects on fetal development, premature labor, and other problems have resulted in the new FDA labeling requirement discussed in chapter 2.

Preparation for Childbirth and Parenthood

Some forms of counseling and education during pregnancy can influence parent behavior at the time of delivery and afterwards in the care of the newborn. Information and support in the months prior to birth can result in a number of desirable parent behavior patterns, including informed participation in the process of delivery, appropriate use of health care, and adjustment to the presence of a new family member.

Many hospitals, obstetricians, family planning counselors, and other health care personnel now urge both parents to participate in classes or counseling preparatory to childbirth. Such education has medical and psychological benefits, helping both parents manage labor and delivery and making the experience of childbirth a positive one. Research evidence suggests that mothers who seek information about labor and delivery in advance tend to require less medication, have shorter labors, and feel more positive toward themselves and their infants afterwards (*5, 6*). Such education or counseling may prove especially important for first-time parents, adolescent parents, and those preferring "natural" childbirth and home birth.

In recent years, a number of private, voluntary groups have offered courses on labor and delivery. Such courses generally are offered in group settings, and complement the counseling and guidance provided in typical prenatal settings. Hospitals, clinics, and group practices also have organized such classes. The Panel views these initiatives very favorably, and sees the need for such education as an integral component of prenatal care. We believe the availability of childbirth education should be increased, with special efforts made to reach low income, minority, and high-risk women and couples.

Similarly, appropriate guidance and support in the period immediately after birth can help a family cope with such questions as infant feeding, how to manage a difficult baby, how to recognize illness, and how to provide a safe and stimulating environment for an infant. Because techniques and styles of caring for and nurturing an infant are largely learned behaviors—albeit shaped by individual temperament, cultural, social, and familial factors—the perinatal period provides a good opportunity to teach parents about child behavior and development. Hospital practices and staff attitudes can significantly affect some child nurturing practices, such as breast feeding (*7*). In addition, positive modes of interaction between parents and infant can to some degree be fostered by hospital personnel and others in the hospital setting. This may be especially important for parents who show ambivalence toward their infant, or those at risk because they have a premature or developmentally disabled newborn.

The perinatal period also is an opportune time to link families to other services or support groups to assure continuous care. One mechanism for such linkage discussed at greater length in chapter 7 is home visiting, which can ease the transition from maternity hospital to home and offer continuous support for a period thereafter. In general, the Panel feels that much more needs to be done by way of parent education before, at the time of, and immediately following, childbirth. Clearly this is a "teachable moment" in the life of every family, and one which deserves more systematic attention. Numerous persons can have a role in parent education: family life educators, primary care physicians, nurses, psychiatrists, clinical psychologists, social workers, and various types of counselors, home economists, religious leaders, teachers, and others (*8*).

The young adolescent mother is in particular need of parent education and support. Often ill-suited developmentally to respond appropriately to the demands of parenthood, she has a major need for guidance. The Panel notes that although some current programs for adolescent parents include a parent education component, this service is not specifically referred to either as a core or supplemental service in present Federal legislation authorizing grants for community-based services to adolescent parents. This oversight needs to be corrected, and experiments further developed with public and private support to teach teenaged mothers and fathers parenting skills.

INFANTS, TODDLERS, AND PRESCHOOLERS

From earliest infancy, behavior patterns of parent and child must be understood as an interactive system. Although it has now been clearly established that some aspects of child behavior are influenced genetically (*9*), it is also clear that behavior of parents toward their children is an important formative influence. For the child, the period from birth to age 5 is one of rapid and dramatic change in developmental capabilities and receptivity to various socializing influences. For the parent, this is a period of maximum potential influence on the child's health and development.

Strong bonding between infants and their parents or other caregivers in the first 6 months of life is regarded as essential to normal emotional development. Taking the infant away from nurturing adults or exposing the infant to only minimally affectionate persons during this period can adversely affect the child's ability to relate to people later in life.

Infants are not passive. They already are able to process information, to associate daily experiences with pleasure or pain, and to form expectations about being attended to when uncomfortable. Moreover, they express clear individual differences in personality, all within the range of normal development (*10*).

Parent expectations about the development of their infant are known to be a strong determinant of child development (*11*). If parents like their babies they will spend time with them. If babies are responsive, the parents will reciprocate and stimulate them. If parents think their babies are somehow defective, parents may ignore them. If the babies greatly complicate their work and leisure life, they may come to resent them. All such parent attitudes can affect the child's well-being over time.

In addition to attitudes affecting emotional and cognitive development, parents adopt behavior patterns which can affect the health of their infants in immediate and practical ways. Appropriate patterns of feeding and nutrition, household safety measures, and scheduled consultation with health care providers all can contribute to the child's long-term health. Very early in the child's life it is still parent behavior, for better or worse, which determines many child health outcomes.

Just as parents exert a unique socializing influence in the first months of life, so the health care and social service systems have a unique responsibility to families at risk during this period. Health care and social service personnel are the only professionals likely to encounter parents most in need of guidance and support. Yet in many areas, the health care and social service systems do not reach out systematically to these parents. The Panel believes that more needs to be done to assure preventive outreach and education to new parents, especially those least equipped to cope with family stress.

There is little opportunity for effective health education when a child's visit with the doctor typically lasts 10 minutes or less and constitutes the only contact with the health care system. Organizational constraints and inadequate financial incentives currently serve as barriers to effective early outreach and education by health care professionals, especially for high risk groups. These constraints are discussed further in chapter 6. They need to be removed to permit age-relevant counseling of parents and children about a wide range of behavioral components of health promotion.

Health-related behavior of parent and child are no less important during the period from 6 to 18 months of age, during which the child learns to walk and to manipulate many of the objects in his or her immediate environment. The likelihood of household accidents goes up significantly during this period. Then from 18 months to 3 years of age, the child undergoes additional rapid developmental changes, including dramatic changes in language and cognitive abilities. During this phase children begin to acquire the dominant beliefs, values, and behavior patterns of their culture, many of which have implications for health.

The age span from 1 year to 3 or 4 years of age is one in which some children "disappear" from public view. They tend not to see health care professionals as frequently as in the first year, but they are too young for preschool and only a minority are in formal day care settings. Hence those designing policies to assist parents of children in this age range have some unique difficulties. Health care and social service personnel remain the most likely source of guidance and education for such parents, and need to give special attention to continuity of parental guidance while the child is still a toddler. Accident prevention, proper habits of eating and hygiene, and other appropriate behavior patterns for the child should be the subject of counseling by health care professionals. Special attention also needs to be given to the risk of child abuse and neglect by parents under great psychological or economic stress. The age range from 1 to 3 years is one in which the demands placed on the parent change in quality and scope, reflecting in part the increased motor competency and assertiveness of the child.

Child Abuse and Neglect

The vast majority of parents take great delight in their children, watching them develop and helping them learn. But almost all parents at one time or another have experienced intense frustration and anger, especially during periods of personal stress, and can understand the impulse to hit or otherwise abuse a child.

Most parents do not actually lapse into such behavior, but an estimated 500,000 to 1,000,000 each year, according to the National Center for Child Abuse and Neglect, do in fact abuse or neglect a child, even killing them in approximately 1 percent of the cases. Abuse can take the form of blows, burns, or sexual assault. Neglect can take various forms, including starvation, confinement, exposure to unsafe environments, or the absence of affection or attention. Children of all ages can be victims, but abuse or neglect often begin when the child is very young.

Because such behavior is aberrant, reflecting extreme parental stress or imbalance, it is difficult for most people to comprehend. For years, professionals and policymakers simply did not acknowledge the full magnitude of the problem, or contemplate adequate steps to deal with it. Within the past 20 years, however, a considerable research literature has developed surrounding family violence, and child abuse and neglect in particular. It is now known that abusive and neglectful parents are found at all socioeconomic levels, and that no educational, racial or religious group is exempted altogether. It is also known that about 90 percent can respond to various new and successful forms of therapy (*12*).

Usually child abuse is the result of a family crisis or series of crises, with some triggering event. Its remedy almost always involves counseling for the entire family, not just the abusing person. Likewise, treatment generally requires a team effort involving numerous professionals, including nurses, pediatricians, child psychiatrists, psychologists, social workers, educational specialists, attorneys, and child care workers.

Because therapy of this kind is expensive, especially if it involves residential treatment, most health and social service experts stress the need for better preventive programs, based on early assessment of family risk, home health visiting by public health nurses, social workers or lay visitors, and vigorous community-based campaigns of education and crisis management. In demonstration projects, preventive efforts have proven highly cost-effective in reducing predicted levels of abuse and averting the costs of subsequent rehabilitation for children and parents (*13*).

The Panel believes that health care personnel—and health policymakers at the Federal, State, and local levels—have a special obligation to work closely with other relevant professional groups on efforts to prevent child abuse and neglect. Because these problems so often are first identified by health professionals, and because good patterns of parent-child interaction are so central to the promotion of child health, health care personnel must take the lead in developing strong preventive outreach and coordination of services for families at risk. Federal, State, and local health programs and policies likewise should take explicit cognizance of efforts in child abuse and neglect prevention in other service sectors, and initiate joint planning and service delivery whenever possible.

Preschool and Day Care

From ages 3 to 6, the child's world rapidly expands beyond the family. Children in this age range are influenced by a wide range of adults, and also acquire new information and behavior patterns from other children.

By 1978, approximately one-third of all 3–4 year olds in the United States attended nursery schools, an increase from 14 percent in 1967. Moreover, 83 percent of all 5-year-olds attended kindergarten in 1978, as compared to 68 percent in 1967 (*14*). Even if many of these programs are only for half a day, they are a logical setting in which to influence health and health behavior positively. Various professional groups, including the American Academy of Pediatrics, American Dental Association, American Nurses' Association, and others have recognized the significance of preschool and day care settings as sites for health education and parent counseling as well as early identification of health problems and linking families with sources of continuing health care.

Approximately 425,000 preschool children from low-income families are presently enrolled in Head Start programs. These programs have proven highly successful in achieving a wide range of objectives, among them health promotion for the child and family. Head Start provides a variety of services from child education to nutrition counseling for parents and supporting services for the family. Improvements in children's cognitive skills achieved by Head Start are "health-related" in that they result in fewer remedial placements and learning problems in later schooling, and lead to better adaptive behavior in many domains. As an effective strategy for health promotion among low-income preschoolers, the Nation should extend Head Start to all eligible children.

The health and dental health education components of Head Start are better developed than similar elements of most day care programs or

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private preschools. Head Start performance standards have required health education for the past several years, a step which the Panel applauds. Other publicly supported and private settings could benefit from similar program elements. In addition, as recommended in chapter 6, the Panel believes that full implementation of the newly formulated Federal day care regulations will be an important means for furthering health education in day care programs, as well as improving health services to children attending these programs.

Television and Young Children

The preschool child learns patterns of behavior in part through direct instruction, but more powerfully through imitation of conduct by adults, siblings, peers in the neighborhood, and persons seen on television.

The influence of television can be seen in children younger than 3, but becomes a major factor during the preschool and early school years. A. C. Nielson Company surveys indicate the average American preschooler spends more than 30 hours a week watching television, for a total of 6,000 hours in front of the tube before he or she ever sets foot inside a first grade classroom. By high school graduation, according to another study, a child will have watched some 15,000 hours of television—versus the 11,000 hours spent on formal education (*15*). The implications of such behavior for the development of a sedentary life style are readily apparent. Further, because role models play a significant part in shaping a child's behavior, the Panel shares with many other groups a real concern about the content of children's television programming and advertising. Television has a great potential for influencing health-related behavior of children, but such influence, at the moment, is largely negative as a result of violence-saturated programming, massive advertising of sugar-loaded and other nonnutritional food, and excessive promotion of over-the-counter drugs.

Program content is determined largely by public demand as interpreted by the television industry. According to a recent report of the Federal Communications Commission (FCC), broadcasters tend not to air a sufficient number of educational or age-specific programs directed toward children (*16*). In fact, of the stations in the 52 markets examined by the FCC in 1977–78, an average of 2.6 hours per week was devoted to such programming. The Panel would urge the FCC to encourage a significantly greater commitment to children's programming.

Controversy continues over the precise degree of influence that television exerts in specific areas of behavior, partly because there is comparatively little rigorously designed research on the subject. However, there is convincing evidence from a series of investigations that television programming and advertising can significantly affect child behavior (*17*). Moreover, if one follows the money, the hundreds of millions of dollars—$600 million in 1978—spent on television advertising directed at children clearly shows manufacturer confidence that at least some behaviors can be influenced via this medium.

Of particular concern for health is the impact of children's food advertising, where the bulk of the money is spent. Until the age of 8 or 9, children lack the cognitive ability to evaluate advertising messages. They have a more difficult time than older individuals in distinguishing fantasy from reality, or exaggerated claims from facts. They also are likely to be gullible (*18*).

Action for Children's Television cites current television advertising tactics as one important cause of poor nutritional habits among children. This notion is supported by the Society of Nutrition Education, whose survey of 1400 nutrition educators found that 89 percent of respondents agreed television undermines their efforts to teach sound nutrition to children. Television advertising prompts children to pressure their parents to buy well-advertised foods, and even parents who successfully resist such pressure feel the strain television advertising adds to their relationship with their children (*15, 18*).

Other concerns involve the influence of television on aggressive behavior, sex-stereotyping, over-the-counter drug use, and drinking. In each of these realms, more needs to be done to present positive models and messages.

Television viewing generally begins to decline after age 12, and older children are usually more resistant to its influence. But for older children as well as younger ones, television-watching limits time available for other possible activities. Exercising, reading, conversing with family members, doing school work, and playing with friends are among the lost opportunities. For the most part, time watching TV is time not spent on learning about life itself.

While concerned about negative influences of television, the Panel is also aware that some television programs have a demonstrable positive impact on children. Productions of the Children's Television Workshop (e.g., Sesame Street) are notable in this regard, as are various other shows produced explicitly for children, including Mr. Rogers, Captain Kangaroo, special science programs, dramatizations for children, and more. In addition, entertainment broadcasting can offer positive health behavior models, and public interest messages and counteradvertising can broaden the information available to children and their parents. Recommendations at the end of this chapter acknowledge the strong potential of television as a vehicle for health promotion.

SCHOOL-AGE CHILDREN

During the elementary school years and into early adolescence, the child develops new cognitive competencies which permit better understanding of health and health-related concepts. During this same period, attitudes and behavior are increasingly shaped by school personnel and peers as well as parents.

School performance, and resulting feelings of success or failure, can fundamentally influence the child's self-concept, with long-term effects on motivation and achievement. Likewise, the seeds of later health-related behavior are often planted during this period. The child gains increasing awareness of his or her own sexuality; observes and may experiment with the use of cigarettes, alcohol, and drugs; establishes exercise patterns and a concept of personal physical capabilities; learns to enjoy or avoid nutritious foods; develops attitudes regarding socially acceptable and unacceptable risk-taking; and begins to make personal judgments about appropriate use of health services. Thus, even as early as the first 3 years of elementary school, attitudes and behavior patterns take shape which can have long-term consequences.

In the school environment, personal qualities, habits, and behavior learned at home are evaluated as well as academic performance. Explicit health and safety knowledge also is imparted. Children are likely to have contact with a school nurse or other health professional without the presence of their parents, and by about third grade they are able to decide for themselves whether to report a personal illness (*19*).

The culture of the school can exert as strong an influence on students as the formal curriculum. Schools vary widely in their academic and social orientation, discipline, and the structure of social groups, all of which can have a bearing on health-related behavior. Many bring children from different backgrounds and age groups together, exposing them to behaviors and attitudes different from those developed in the child's own home or neighborhood. Programs to promote good health-related habits via the schools cannot hope to succeed without acknowledging the powerful influence of school culture and adopting educational approaches which build upon its positive aspects rather than ignoring it altogether. Likewise, school personnel must understand the "infra-curriculum" represented by their own health-related behavior, and not expect this to be any less influential than classroom instruction.

School health promotion can take many forms: formal classroom education, supervised field experiences, peer education, education as part of the delivery of health services, physical education activities, and teaching in conjunction with food services. Even though many schools and school systems are overburdened with their tasks of teaching basic skills, many national parent, educator, and health-professional groups have urged that all schools take action to strengthen health and safety education. Such education must be integrated with, and reinforced by, many aspects of school culture and many parts of the curriculum.

Classroom Instruction

Because more than 95 percent of children and youths from 6 to 18 can be reached via the schools, there has always been a strong rationale for using schools as a site for formal instruction in health and hygiene. Health education has been a regular part of school life for decades, and earlier in the history of public education in this country it was considered one of the basic subjects.

There also have been periodic national efforts to define and revise the health education curriculum. It is interesting, for example, to compare the recommendations jointly made by the American Medical Association and National Education Association in 1911 with those of the National School Health Education Curriculum Study in 1967. Both were landmark statements for their times. The 1967 recommendations, framed around the fundamental concepts of growth and development, decisionmaking, social interaction, and strategies to resist peer and media pressure, remain very relevant in 1980, although their implementation has been far from adequate in most school systems. Even now, only 18 States require comprehensive health education in grades K–12 (*20*).

Some progress has been made, nonetheless. In many school districts, those responsible for health education are employing more sophisticated approaches to reach their objectives, with measurable positive results. Several recent studies have shown demonstrable effects, for example, from innovative programs designed to reduce smoking among youngsters (*21*).

In their enthusiasm to find solutions to existing health problems and to meet immediate needs, many voluntary groups and health agencies have developed teaching materials on specific topics especially for school use. Such efforts have helped fill a void, and are to be commended, but the number of health problems deserving special consideration in the curriculum has become so great that many of these teaching aids can only be useful if they are part of a comprehensive and sequential health education program. In the absence of a comprehensive program, school administrators under community pressure to "do something" about drugs, sex, smoking, alcohol, or other problems too often must respond with a hastily scheduled 2-week unit or a lecture to cover a specific problem—a problem often forgotten the next year in order to concentrate on something else.

Fragmented education efforts of this kind are not an adequate response to the need for better health education. Federal, State, and local health and education agencies need to promote a unified approach to health teaching, organized so as to encourage coordination with other subject matter and evolving sequentially through the school years in developmentally appropriate steps. Health promotion and disease prevention should be emphasized, including the anticipation of experimentation with certain behaviors at certain ages.

Appropriate content areas for school health education curricula are many and diverse. They include, at a minimum, nutrition, exercise, smoking, alcohol use, driving safety, human sexuality, family development, coping and stress management, and environmental conditions affecting health. This is not as overwhelming a list as might be supposed, because many of the same basic concepts and skills underlie appropriate behavior in all of these domains.

The content of health education remains a matter for local determination. But Federal and State authorities, in conjunction with health professionals and educators have done a good deal in recent years to develop model curricula and teaching materials. Current Federal efforts to stimulate and improve school health education are being carried out by a variety of offices within the Department of Health and Human Services and the Department of Education, with some resulting problems of fragmentation. There is considerable variation not only in subject matter but in approach, from categorical (e.g., alcohol education) to more general health enhancement (e.g., esteem-building, development of coping skills). The Education Department now has an Office of Comprehensive School Health, which is in a position to coordinate all Federal school health education programs and to work with State and local education agencies to develop such programs. In addition, through passage of the Health Education Amendment of 1978 (P.L. 95–561), Congress paved the way for establishment of demonstration and pilot projects in comprehensive school health education. As yet, however, no funds have been appropriated to implement the new law.

If school health programs are to be effective, improved preparation and in-service training of teachers, school nurses, physical education instructors, and other school personnel also will be necessary. Elementary school teachers typically lack training in this field, and only 22 States certify secondary school teachers in health education. Similarly, in many cases school nurses and physical education personnel are not sufficiently oriented to the potential contributions they could make to preventive health education and health promotion, and are not given health education roles in the schools. Public and philanthropic grants to training institutions and local and State education agencies for preservice and inservice training could have a major effect in changing this situation.

Physical Education

School physical education programs are an area of vast unrealized potential. While adult participation in exercise and sports has been soaring in recent years, cutbacks in public school budgets have resulted in a decline in the quantity and quality of school physical education programs. Only one child in three now participates in a daily program of physical education, and the record is worse in many areas (*22*). Lack of adequate programs is particularly notable in congested central cities. A recent survey of New York State elementary schools showed four out of five had not met State-legislated requirements for physical education in the preceding year. Coupled with the prevalence of after-school television viewing, this decline in physical education is cause for concern. One of every six children taking a simple screening test designed by the President's Council on Physical Fitness and Sports currently fails the test (*23*).

It is important to reverse this trend, and also to increase the emphasis of physical education programs on lifetime fitness and health maintenance skills. School programs can have an impact, for both sexes, far beyond the development of specific athletic skills for competitive team sports. Team sports help students learn to subordinate personal glory to group achievement, but the skills involved in some individual sports, such as bicycling and hiking, also should be taught so that young people are not dependent on the presence of others for physical activity. They should learn to set and achieve personal standards of physical performance as well as, or as an alternative to, competing against others. Physical education instructors also should teach the proper responses in situations of physical strain, techniques of relaxation under conditions of emotional stress, and the relation of nutritional intake to physical and mental activity.

Implementation of school-based programs reflecting these principles will require a reassessment by many communities of physical education priorities. In some instances, communities may need to secure expert advice and support from local, State, or national sports medicine and fitness councils. The Panel believes that one group well-suited for a leadership role is the U.S. Olympic Committee. Additional groups with valuable expertise include the U.S. President's Council on Physical Fitness, the American Academy of Pediatrics, the American Nurses' Association, and others.

Health Education in School Health Services

School-based health services, whether they involve the traditional school nurse or a full-service clinic, offer the potential for teaching children about prevention, self-care, and the wise use of health services. Part of this potential, alluded to above, is in redefining the role of the school nurse so that she spends more time in teaching and counseling activities relating to health promotion and disease prevention. School nursing associations, in collaboration with other professional groups and experts on prevention, need to examine this issue and devise a preservice and inservice training agenda for the 1980's.

School health services can also teach children appropriate patterns of health care use. Recent research in the schools of southern California suggests that patterns of use of school health services are established early in elementary school, with a limited number of children making most of the visits to the school nurse (*24*). Some children may actually need more care, but it is equally likely that the pattern reflects underutilization by some and overutilization by others, as a function of different degrees of classroom stress, willingness to seek help, or rapport with school health personnel. Whatever the case, health services in the schools offer a good vehicle for counseling children about personal decisions regarding use of health services, whether for sick or well care.

A third important role for school health personnel is to work with students and teachers to increase understanding of the particular problems of handicapped and chronically ill children. With the advent of P.L. 94-142, the Education for All Handicapped Children Act, many handicapped children now are being mainstreamed who previously might have been in separate classes or institutions. These children often have special health needs as well as learning needs, and effective integration into normal classrooms requires orientation of other students as well as sensitivity in addressing the health-related concerns of the handicapped themselves.

ADOLESCENCE

In recent years, much attention has been given to adolescence as a crucially important and often neglected period of the life cycle. Early adolescence, which can be roughly equated with the ages 10–14, is a time of rapid physical, cognitive, and emotional change, accompanied by the often stressful shift from elementary school to junior high school or

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middle school, and concomitant entry into "teen culture." Later adolescence is a period of transition to adulthood, during which young people are introduced to a wider social and occupational world, and gradually required to adopt fully adult norms of personal conduct.

Although adolescence is a life stage in which many forms of experimentation are necessary, socially adaptive, and to be encouraged, it is also a time when youngsters typically try out a number of behaviors which are risky or may have unfortunate lifetime consequences. Some forms of health-related behavior, such as eating and exercise habits, may already have been set earlier in childhood. Others which are part of adulthood, such as driving conduct and sexual behavior, are formed either wisely or poorly during this phase of development. Still others, including smoking and alcohol and drug abuse, can be more like "time bombs" ticking away through youth to explode years later in the form of chronic illnesses such as heart disease, cancer, or stroke.

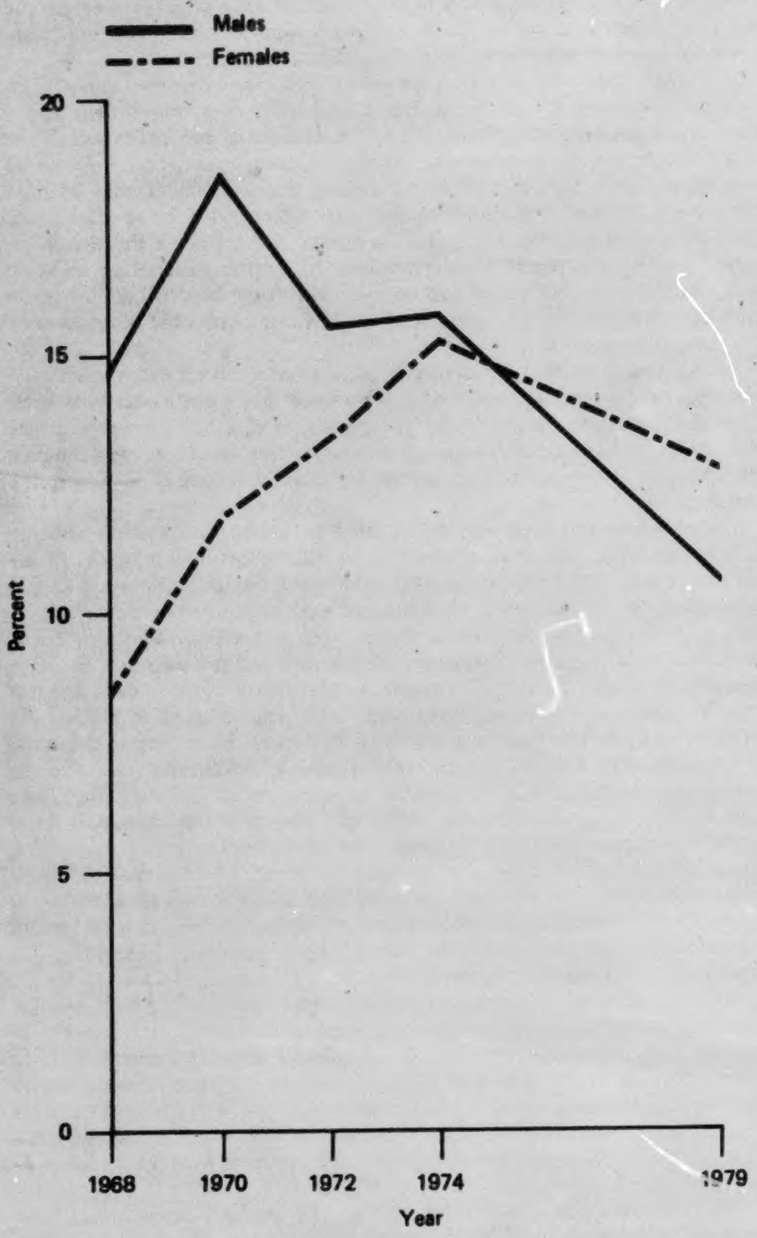
Many health-related problems of adolescence result from immature judgment combined with uncertain self-esteem and strong peer pressures. One such problem is unwanted pregnancy, which has grown with the dramatic increase in percentages of sexually active teenagers over the past two decades. The topic of sexual behavior in adolescence is discussed in a separate section below.

Other behavioral problems result from experimentation with personal habits which are prevalent in the adult world. Unfortunately, many of the risk behaviors which pose a threat to adolescent health and life are deeply embedded in the country's adult culture and are therefore perceived by teenagers as desirable symbols of independence, maturity, and sophistication. The most prominent examples are alcohol and tobacco use, and also use of mood-altering drugs, especially marihuana. Survey data suggest that 70 percent of all 12- to 17-year-olds have experimented with alcoholic beverages, 54 percent have smoked, and 31 percent have tried marihuana.

Experimentation does not necessarily lead to continuing use of these substances. In 1979 the percentage of teenagers smoking, for instance, was just 11.7 percent—well below the proportion of those who had tried smoking at some time in their lives. This figure also represents a decline from 1974, when 15.6 percent of all youngsters 12–18 years old were current smokers. However, the trend for alcohol and marihuana use is not so positive. Between 1975 and 1979, the percentage of high school seniors reporting alcohol use within the last 30 days increased from 68 to 72; reporting recent marihuana use, from 27 to 36 percent.

While a number of teenage behavior patterns have implications for long-term adult health and longevity, some can and do result in immediate death or disability. All of the major causes of mortality and morbidity among teenagers are related to behavior and the social environment, and usually involve temporary misjudgment, anger or depression combined with newly acquired access to instruments such as automobiles and guns. Inappropriate use of alcohol and drugs often interacts with these factors to multiply risk.

While death rates for all other age groups in the United States have declined steadily since 1900, those of young people ages 15–24 actually have increased by 11 percent since 1960 due to the high toll of accidents



Current cigarette smoking by youths 12-18 years of age, according to sex: United States, 1968-79, selected years

Note: Current smokers are defined as those who smoke one or more cigarettes per week.

and violence among teenagers. Accidents (especially in motor vehicles), homicide and suicide account for three-quarters of all deaths in this age group. Among white adolescents, accidents are the leading cause of death, two-thirds of them in motor vehicles. Among nonwhite adolescents, homicide is the leading cause of death.

Increased suicide rates among teenagers, no less than homicide rates, are a tragic social problem. Between ages 15 and 24 years, suicide is the third leading cause of death among males and fourth among females. For 10- to 14-year-olds and 15- to 19-year-olds, overall rates have more than tripled between 1950 and 1977. Suicide involving use of firearms has doubled for the age group 15–24 since 1966 (*25*). In some cases these data reflect the presence of major psychiatric disorders, but in many others they reflect the above-mentioned interaction of factors such as temporary stress or despondency, experimentation with alcohol or drugs, and the availability of automobiles and guns. It is worth noting that these estimates are probably conservative, because suicidal impulses may contribute to many deaths identified as accidents.

Positive Influences

Those who have worked with adolescents have gradually come to understand that enhancement of self-esteem—of pride in the youngster's own capacities and accomplishments, which in turn encourages an optimistic view of the future—is a most promising strategy for promoting health-enhancing behavior. Adolescents are seldom impressed by admonitions about present dangers like automobile accidents (they "can't happen to me") or by warnings of long-term consequences, such as a heightened cancer risk from smoking. Similarly, it is very difficult for adolescents to take actions that will put them out of step with others of their age, which means, for example, that personnel trying to prevent harmful or promote healthful behavior often must focus on changing the group's attitudes rather than the individual's.

While the influence of peer pressures on adolescent behavior is widely recognized and well documented, it is also important to remember that family members—both parents and siblings—remain major sources of guidance and are influential role models. Firm and steady guidance from parents can be particularly important during early adolescence. This point is often overlooked, as we are reminded by two leading psychiatrists, Drs. Beatrix A. and David A. Hamburg:

> In an effort to foster the perceived value of independence in the child, there may be a significant renunciation of parental prerogatives. This is largely inappropriate for the early adolescent . . . generally, there is a heightened need for parental stability and guidance at the time of major biological, school and social discontinuity. The early adolescent cannot possess the competence and mastery needed for full independence (*26*).

As adolescence progresses and youngsters renegotiate their relationships with parents and other family members as part of the gradual move to independence, teenagers care deeply that they be able to manage at least some aspects of their lives with autonomy and privacy, as adults would. This attitude has major implications for the design of educational and counseling services to meet adolescent needs.

Important elements of health education and counseling for adolescents can be provided through both the health care sector and the schools. Adolescents need more information about the effects of their lifestyle on their present and future health, but this information must be presented in ways which are likely to influence their attitudes and behavior. Studies indicate that the vast majority of adolescents already know smoking causes cancer, that unprotected intercourse can lead to pregnancy, that proper diet, exercise, and rest are essential for good health, and so forth. The problem is that they do not always act prudently on the basis of this knowledge, and often seriously underestimate the consequences of certain types of risk.

Recognizing this fact those most successful in working with adolescents regarding their health have often designed innovative programs and techniques for meeting the unique needs and values of the age group. Effective counseling and education for teenagers can be found in health clinics, multiservice centers, the schools, and community programs sponsored by religious groups, scout troops, and various private associations. There is no single "right" place or mechanism to teach adolescents. Instead, a variety of approaches, with overall community coordination, need to continue and be expanded.

Primary health care providers obviously have an important role to play, both in offering anticipatory guidance to adolescents and their parents, and in helping to create and sustain community education efforts for teenagers. Because so few adolescents see a doctor unless they are sick, extra efforts are needed from primary care physicians—general pediatricians, family practitioners, obstetricians, and internists—to ensure that any component of their practice time devoted to adolescents includes an appropriate emphasis on preventive efforts and health promotion, including counseling. Physicians also have a special responsibility to take initiative in creating and strengthening health-related programs for adolescents in the school and the community. The specialty of adolescent medicine can continue to provide badly needed leadership in prevention and health promotion for this age group, and counseling and education directed at adolescents also should continue to come from a wide range of nonspecialists and personnel other than physicians.

School Programs

For adolescents as for younger children, the schools offer a promising site for health education. But students who find their studies interesting and engaging are more likely than troubled students to be interested in their health and to absorb important health messages. If school is a "hassle," if the days are filled with boredom, if self-esteem is low, alternative sources of satisfaction and of challenge will be sought, which may include activities with a negative health impact.

Comprehensive, innovative school health education can promote healthy habits among adolescents and discourage the adoption of health-damaging behavior. But as previously indicated, there is much room for improvement in most school systems' health education efforts. This is particularly true of health education aimed at adolescents, which in the past often has been fragmentary and generally perceived by the youngsters themselves as off target.

There now are some programs under way in various school systems around the country which have proven effective in helping students understand the relationship between behavior and health and in teaching them to resist pressures from peers and other influences to start smoking, drinking, etc. Most such programs emphasize the active involvement of students, the use of teenagers to counsel their age peers or younger children, and the teaching of coping skills to help children anticipate and resist peer pressure.

One example is in a school-based program in San Jose, California, where 10th grade students worked with younger children in the 7th grade to identify and diffuse pressures which encourage smoking. Two years after the program commenced, participating schools found a 50 percent decrease in the number of younger children starting to smoke as compared with control schools without the peer counseling program (*27*).

Another project which showed significant success was conducted in Houston, Texas. Youngsters were tracked from seventh through tenth grades as they were exposed to a series of videotapes, film and poster anti-smoking messages featuring adolescents of about the same age presenting information or engaging in role-playing. During the years of the program and in a followup study 2 years later, researchers found a significant reduction in the onset of smoking (*28*).

Schools and community agencies also are developing extracurricular programs to channel the strong influence which peers have on health-related behavior. Such programs take different forms, including the education of younger children by trained older students and the education of age mates by trained students. Some of these programs are very large in scale. For example, in New York, teams of high school students, each with responsibility for its own format, visited 71 elementary schools, reaching nearly 10,000 fifth and sixth grade students. A Minnesota peer group model program called "Teenage Health Consultants" provides information and training to adolescents who then become health educators and make referrals within their peer groups (*29*). This program, replicated in communities as well as in schools, is concentrated mainly on drug use/abuse, human sexuality, mental health, food awareness, and community health resources. Likewise, family planning clinics, such as that offered by the city health department in Berkeley, California, have developed model outreach education and inpatient counseling programs.

Education in Human Sexuality

Among the most important, and also most controversial, topics taught in the schools is sex education. Sex education is singled out for special comment because of the importance of responsible sexual behavior to the health and well-being of adolescents, and because this subject highlights the need for families to play a more active role, along with health care providers, community agencies, and the media—not just the schools—in preparing and protecting young people.

Although the teenage birthrate is now declining for all adolescent age cohorts, sexual activity among teenagers continues to increase. It is now estimated that approximately 50 percent of unmarried young women 15–19 years old living in metropolitan areas have had sexual intercourse, significantly more than the 30 percent reported a decade ago. Approximately one-third of sexually active teenage women get pregnant, a higher rate than a decade ago even though there appears to be more use of contraception. This fact may reflect use by teenagers of less effective methods of contraception, or more frequent intercourse among those who are sexually active, or both.

Among those teenagers who do get pregnant, the percentage who marry before the end of pregnancy is declining—from 33 percent in 1971 to 16 percent in 1979. Of those who remain single, only about half have the baby, as compared with approximately two-thirds a decade ago. The rest either suffer miscarriages or opt for abortion (*30*).

In 1977, some 31 percent of a reported 1.3 million abortions were obtained by women under the age of 20. In fact, there were more abortions (12,964) among girls under 15 than there were live births, and among girls 15–17, some 135,801 pregnancies—or almost 39 percent of all conceptions—ended in abortion. About 17 percent of all infants born in 1977 were born to teenagers, and birth rates among black teenagers remain much higher than those among whites. A few more than twice as many blacks as whites aged 15–19 gave birth in 1977 (*31*).

It has frequently been assumed that a large percentage of teenage pregnancies are unwanted. The Centers for Disease Control have estimated that in 1977, 46 percent of teenage births and 70 percent of all teenage pregnancies were unintended (the difference accounted for by abortions). However, recent studies indicate that unintended is not necessarily synonymous with unwanted, at least among those who carry their babies to term. One Philadelphia study of black teenagers 13–18 years old found only 35 percent felt having a child would make life "worse" or "ruined," while 22 percent thought it would make life better or no different and 43 percent didn't know what the effect would be. A variety of emotional factors appear to be involved in teenage pregnancies, including a desire for love and acceptance, for "proof" of maturity, for status with peers. Adolescents are seldom aware of the adverse impact early birth will have on their own future education and income, or of the expense and strain inherent in child rearing.

Sexually transmitted diseases are another major health problem of young people ages 15–24, who account for approximately 65 percent of the estimated 8–12 million cases of these diseases each year (*32*). The most common of the sexually transmitted diseases include trichomoniasis, gonorrhea, nongonococcal urethritis, genital herpes and syphilis. Several can lead to serious complications. In young women, for instance, pelvic inflammatory disease from both gonococcal and nongonococcal infections is the leading cause of infertility and sterility; it afflicts an estimated 1 million people annually. Genital herpes can cause severe neurological damage to an infant born to an infected mother.

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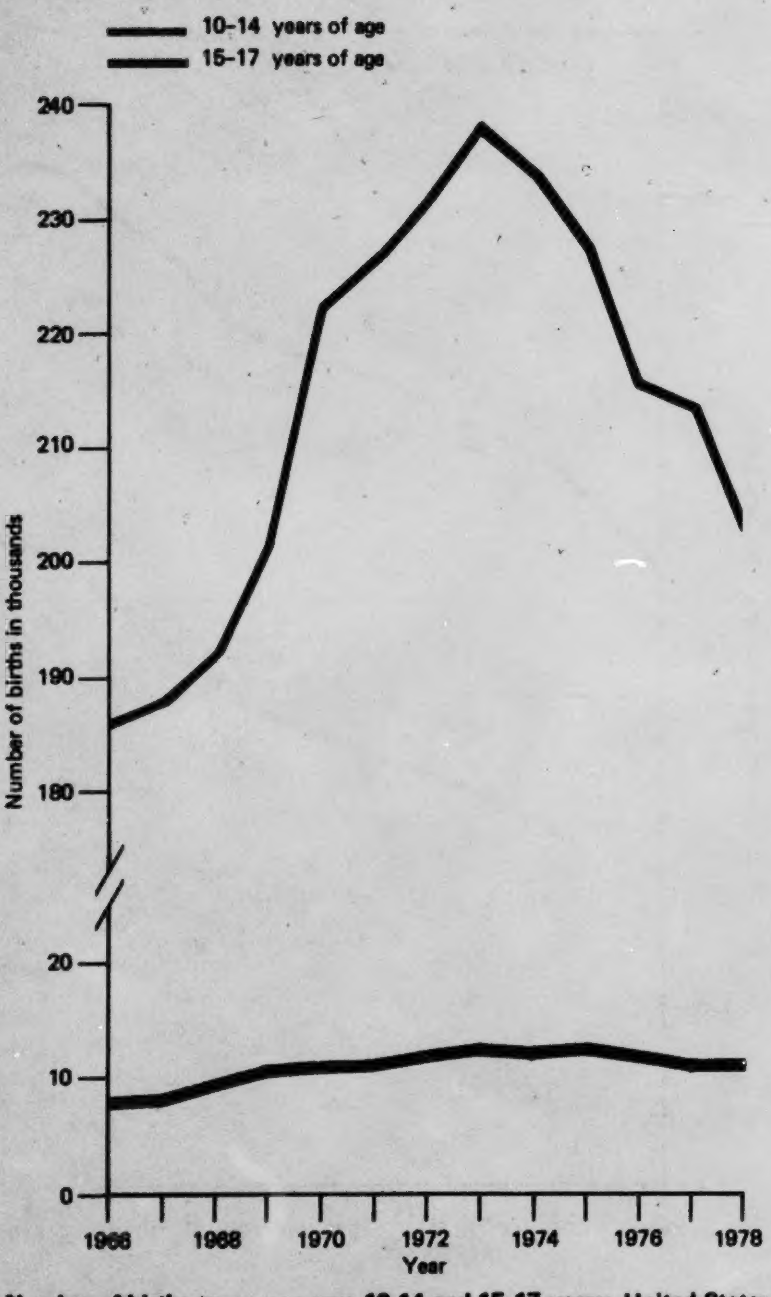
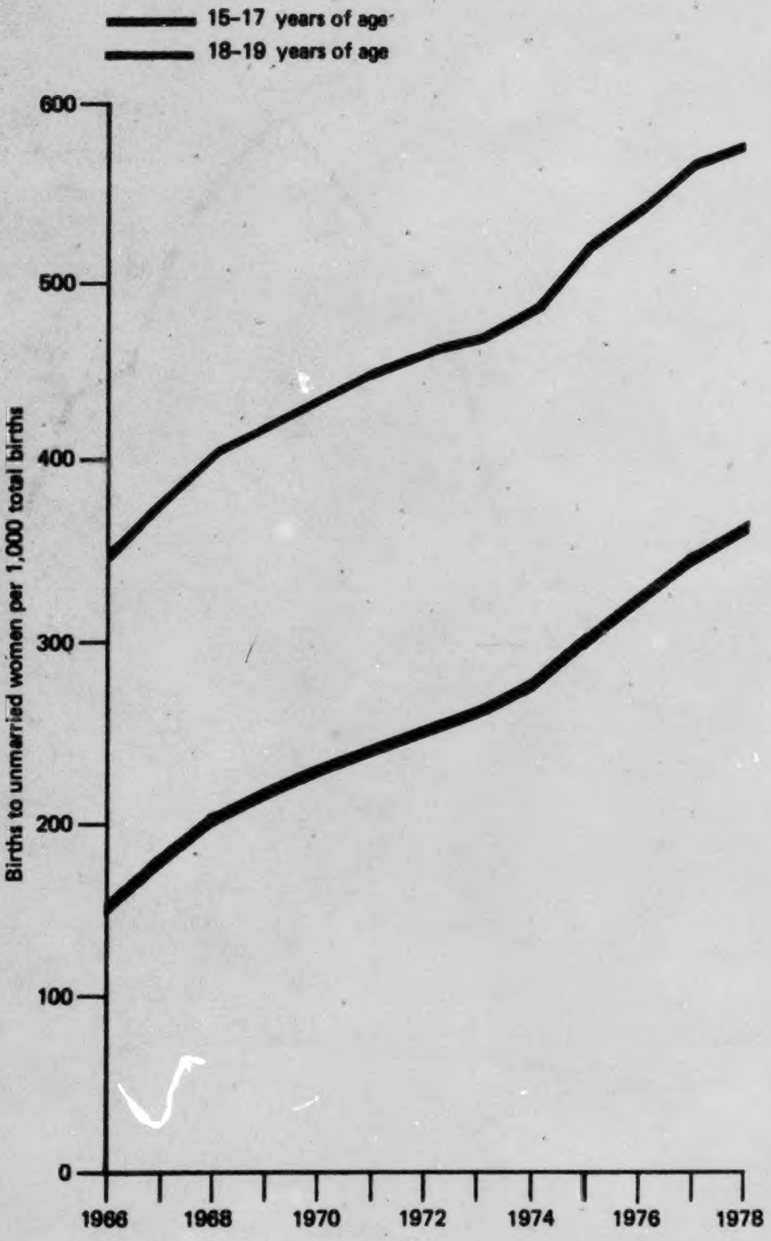


Number of births to women ages 10-14 and 15-17 years: United States, 1966-78



Live births to unmarried women 15-19 years of age, per 1,000 total births, according to age: United States, 1966-78

The traditional response to the health threat posed by a high incidence of teenage pregnancies and sexually transmitted disease has been a call for improved sex education programs and more effective use of family planning services—and indeed, this Panel would echo such suggestions. But we do not want to suggest that the underlying cause of the high incidence of these problems—the increasingly widespread sexual activity among adolescents—can be ignored. It is reasonable to suggest that a reduction in early sexual activity would be the best way of reducing teenage pregnancies and sexually transmitted diseases.

Teenagers are subjected to enormous pressures—from peers, older friends and role models, the media and other influences—to engage in early and frequent sexual activity. Nothing in American society is more glamorized than sexual "love," and sources of adult guidance do not always make clear that there are excellent reasons in addition to moral injunctions to go slow in this area of life experience. The Panel believes sex and family education courses—and guidance offered by parents, teachers, religious leaders, and health care providers—should explore and clarify the implications for physical and mental health and for personal growth and development, of early sexual activity, of early pregnancy and child rearing, of sexually transmitted diseases, and of abortion.

Such data as are available indicate that there is very little communication about sex in the home. Among 7th grade girls, one study found that 20 percent of mothers had never told daughters about menstruation, 50 percent had not discussed the male role in reproduction, and 68 percent had not discussed any aspect of birth control. This is in spite of the fact that the impact of parental communication about sex has been shown to be significant. Research has indicated that strong supportive family ties help to "innoculate" teenagers against early pregnancy. Even minimal sex education from the parent is associated with postponement of age of initiation of sex activity (*33*). Research suggests that school and community sex education programs which involve parents actively and seek to improve parents' communication with their children would be helpful. Furthermore, the experience of many communities around the Nation indicates that active involvement of parents in the development of school-based sex education courses is often crucial to their acceptance and effectiveness (*41*).

Sex education is now fairly widespread in American schools. Seven in ten never-married women aged 15–19 have had a sex education course, and about half have had courses which included some teaching about modern contraceptive methods. Six in ten have had some formal instruction about venereal disease and seven in ten have had detailed information about the menstrual cycle (*34*). There is, however, still considerable room for improvement in the provision and scope of sex education programs in the schools.

Because sexual learning is social learning, it must be understood broadly as a life-long process beginning at birth and continuing into old age. Very little of the information, attitudes, values, and behavior patterns important for understanding sexuality are learned by children, adolescents—or for that matter adults—in a formalized manner. Most school-based approaches to sex education remain more narrowly "reproductive education," meager in content, limited in scope, and too late in being presented. Rarely do they provide opportunities for youngsters to discuss aspects of sexuality relevant to decisionmaking and self-understanding, such as affection, love, emotional intimacy, body image, gender roles, dating, marriage, divorce, family responsibility, and lifestyles. Moreover, parents often do not provide such information to their children. In general, neither the college professor, nor the businessman, nor the assembly-line worker presently talks to his or her child about these matters (*35*).

The Panel therefore believes that sex education programs must address more than the elemental facts about human reproduction. Such programs should cover the health implications and life impact of sexual behavior; the effectiveness and risks of various contraceptive methods, including abstinence; the physical and emotional risks of abortion; the emotional and social ramifications of sexual activity. They should also focus on clarifying personal values, maintaining self-esteem, and developing responsible interpersonal relationships. We also believe that abstinence from early sexual intercourse should be treated as not merely acceptable but in most cases as preferable.

Likewise, young people need repeated opportunities to discuss the same information. As youngsters get older, their bodies change, their social awareness changes and they have new feelings to understand and cope with. Too many parents and professionals subscribe to an "innoculation theory" of sexual learning—one discussion will do it. In fact, information on reproduction at the age of 10 or earlier has a very different meaning than the same information at age 17.

There is a strong need for educational efforts to reach adolescent males on these issues as well as females. Sexuality is not just a women's issue. It is notable, for example, that less than 1 percent of Planned Parenthood services reach males.

Although school programs remain an important focal point for educational programs, it is not enough to expect schools alone to assume a teaching responsibility. Health care programs and youth programs throughout the community, as well as the media, should incorporate at least some elements of health promotion in regard to sexual conduct.

Role of the Media

The mass media—especially television and radio—can help shape healthier behavior among adolescents, not only in regard to sexual conduct but also on a wide range of other matters. Entertainment programs, such as popular situation comedies, offer an excellent opportunity for presenting health information in a format that appeals to a wide range of viewers. Radio stations specializing in rock or disco music also reach teenagers of all socioeconomic levels and can be used to disseminate health-promoting messages. To be effective, however, such messages must be carefully tailored to adolescent concerns and delivered in a way that captures the teenager's attention. In addition to working with the media in developing health promotion material, the Panel would urge that groups concerned about adolescent health discuss with television scriptwriters and network and local officials the content and balance of both programs and advertising. As Norman Lear, the television producer, told an Action for Children's Television Conference (*36*):

> We have learned that more people will absorb information when it is couched in entertainment.
>
> A half-hour documentary on seat belts in automobiles will make only so many converts, largely because the audience is smaller, but also because people resist being lectured to. But have Archie Bunker or Fonzie or Mork or Mindy strap themselves into a seat belt, and there will be a run on seat belts in stores everywhere within the week.
>
> The question, then, is how to get more information, more positive attitudes about humanity, and more accent on better values into the mainstream of television programming. The first thing is to work harder at raising the consciousness of network programmers, independent producers, actors, directors, and writers—all those who contribute to the media.

POLICY IMPLICATIONS

Previous sections of this chapter have reviewed health-related behavior of various age groups, commented on education and counseling needs relevant to each, and mentioned teaching strategies of demonstrated effectiveness. Implicit in this discussion has been the notion that, although much health-related learning takes place via family and peers outside of formal programs or teaching efforts, there are five institutional structures—the health care system, the schools, the media, the workplace, and the community—through which public policy may exert a positive influence.

In making recommendations relevant to these major institutional sectors, we are mindful of several general facts.

First, although health-related behavior has multiple determinants, and the influences of socialization and cultural transmission are certain to be more powerful in cumulative effect than any single program or policy to effect change, health education nonetheless can be a very effective tool when educational ventures are properly designed and executed. It is the Panel's impression in reviewing the results of various recent demonstration projects that much more is known about what makes health education effective than is being applied.

Just as health-related behavior has multiple determinants, so behavioral risk reduction is best achieved through a multifaceted approach. Messages communicated via more than one setting or mechanism can have a cumulative impact. Health care providers, schools, mass media and the community are more likely to succeed in influencing behavior if they coordinate their efforts, or at least reinforce—rather than contradict—one another.

It is also true that information alone rarely produces behavioral change. This means that we cannot expect to change important behaviors such as use of prenatal care, eating habits, patterns of oral hygiene, contraception, and so forth simply by making information available about them. It is also naive to assume that individuals can be well taught at little or no effort or cost, or without expenditure of time. Effective educational and counseling strategies will continue to require careful community-wide planning, imaginative design and execution, and focused followup evaluation.

Lastly, if efforts to help individuals adopt desired behavior are to be based on the complex realities of life, and on available evidence about what works in health education, then greater emphasis must be placed on approaches which:

- address the practical limitations which individuals face in trying to act in health-enhancing ways
- direct attention to institutional and other higher level change in addition to individual change
- emphasize informed decisionmaking over behavioral prescription, and avoid unethical intrusions on personal freedoms
- reduce the barriers to individual action, such as requirements of time, undue technical knowledge, effort, and cost
- are based on systematic assessment of the causes of behavior which contribute to the health problem in question
- focus on the full cycle of behavior change, from assessment of factors predisposing an individual to certain behaviors, to analysis of what might promote change, to reinforcement of change when it occurs
- involve the group or groups to be affected in program design and implementation
- meet the minimum threshold level of program effort needed to have an impact.

These are some of the basic attributes of any program or policy to enhance personal health-related behavior.

Health Care Settings

As noted throughout the chapter, health care settings are obvious sites for initiating health education, guidance, and counseling for pregnant women, children, and adolescents. Moreover, the role of health care professionals in initiating, supporting, and participating in such efforts may extend beyond the health care delivery site to the school or to other community settings and programs. Because many people place high value on health information from health care providers, the health professions are in an unusually favorable position to offer effective health education and counseling.

The Panel therefore recommends that regardless of organizational setting, *primary health care for children and pregnant women should place greater emphasis on patient education, guidance, and counseling directed to parents and children, especially as these relate to health promotion and disease prevention.*

- Family planning services should include a substantial component of counseling and education.
- Counseling and anticipatory guidance about behavioral risks should become an integral part of all prenatal care, and women

seeking to change behaviors such as smoking and alcohol use should be assisted by providers directly or through referrals.

- The availability of childbirth education should be increased, with special efforts to reach low-income and high-risk women and couples who typically have not had access to adequate preparation for childbirth.
- Increased emphasis should be given in the health care system to parent education, guidance, and counseling, particularly in the vulnerable perinatal period and during infancy. Parents having difficulty in adequately nurturing and caring for their children should be provided with continuing counseling, education, and support.
- Health professionals should assign high priority to health education, guidance, and counseling for preadolescents and adolescents, and their families. Health services for these groups should include appropriate education and counseling on human sexuality, and the risks involved in behaviors such as smoking, alcohol use, and use of drugs.

In making these recommendations, the Panel acknowledges that substantial attitudinal, financial and organizational barriers impede their full implementation. These are discussed in later chapters. Access to health care providers remains episodic and crisis-oriented for some populations, and as yet only some physicians and other primary health care personnel see it as their role to spend a significant component of time on health promotion and primary prevention.

Techniques of counseling and education that deserve added emphasis in health care settings include one-to-one counseling, group discussions, "exit interviews" (as in the use of a nurse or trained lay person in family planning clinics to clarify and reinforce health recommendations), outreach services, and telephone-access and cassette libraries of recorded health information. Significant involvement in school and community health promotion activities remains highly desirable, as the Panel sees it, for private practitioners as well as other health care providers.

To reinforce and further stimulate health education and counseling via the health care sector, *the Panel further recommends that Federal policymakers take the following steps as part of a broad national strategy to introduce appropriate emphasis on health behavior in health service programs:*

- Maternal and child health authorities in the Department of Health and Human Services should expand the Department's capacity to convey specific educational "messages" regarding information which is important for the promotion of child health, including such content areas as breast-feeding, infant nurturance and stimulation, continuity of parenting, nutrition, child safety, and adolescent behavior. These messages should be disseminated widely via Department programs, the media, voluntary organizations, and health care providers.
- All standards for quality of care should reflect the importance of counseling and education for parents, children, and adolescents, and all federally supported health service programs should be

monitored to assure adequate emphasis on these components of care.

- Further support should be given, through various Federal health programs and policies, to counseling and education related to family planning, prenatal and postnatal parent counseling, childbirth education, and guidance for the parents of children and adolescents.
- Training in the content and methods of counseling, guidance, and education for parents, children, and adolescents should be made part of all training programs for health care professionals, and information should be disseminated by the Department of Health and Human Services, as well as private foundations, professional associations, and certifying bodies regarding successful clinical training programs for the teaching of parent and patient education to health professionals, so that other programs can be strengthened.
- Continuing education programs should give increased emphasis to counseling, guidance, and health education skills for all health professionals, especially those practicing in primary care settings.

The Schools

The schools are receiving renewed attention as sites for disease prevention and health promotion just when many are under severe financial constraints and are hard-pressed to accomplish other basic tasks. However, certain excellent programs attest to the potential success of health education—as a part of health services, in the classroom, in physical education programs, in extracurricular activities, and as a product of a healthy school climate of discipline and respect for students.

The Panel deeply respects the traditional autonomy of local school districts in making curricular decisions. We nonetheless believe that all of the Nation's school districts should have appropriate and high quality health education and counseling. It therefore seems to us essential that *public education authorities at all levels should make a strong commitment to promoting healthful behaviors among children and better understanding of the determinants of lifelong health.*

- Education regarding health should be an essential component of the school curriculum at all grade levels. School programs should assume a developmental perspective, encourage active involvement of parents, teachers, nurses, nutritionists, physical education personnel, and home economists, and be designed to enhance student decisionmaking about health behavior.
- Local school boards, superintendents, and elementary and secondary school principals should take whatever steps are necessary to ensure strong working relationships in health education among school personnel, parents, and various community health resources outside the schools, including local health care providers.

- Physical education programs in primary and secondary schools should include instruction in individual exercise, lifetime fitness, and other health maintenance skills in addition to competitive team sports. Such programs should be designed to foster the student's own sense of self-esteem and competence.
- Every elementary school teacher should receive adequate preparation in health education as a prerequisite to certification, including exposure to curricula, methods, and materials, and instruction in the role of health services in the school and community. In addition to understanding general health content, teachers should gain basic skills in managing school-related problems of chronically ill or handicapped children and assisting these children in the classroom.
- Science teachers, physical education instructors, school health personnel, home economists, and others who have special opportunities to provide health education should be encouraged by local school boards, superintendents, and principals to seek relevant preparation and continuing education.
- Parents should play an active role in informing and deepening the understanding of young people about sexual behavior, both as participants in the development of school sex education courses and directly within the family. Courses in human sexuality, taught by competent persons and with the full participation of parents, should be available in the schools. Developmentally appropriate courses should address more than just the elemental facts about human reproduction, dealing with sexual development in the broader context of social and emotional development, value formation, and responsible interpersonal relationships.

These steps will require vigorous commitment by local and State school boards, superintendents, principals, teachers, and other school personnel. They also will require the full support of local health care providers, and willing collaboration by State health authorities.

The Federal Government also can play a significant role in advancing school health education, by developing and disseminating curricula, supporting demonstrations, and otherwise facilitating knowledge transfer. No consistent Federal coordinating mechanism or policy with clearly articulated school health objectives has yet emerged.

Current Federal efforts to stimulate and improve school health education are now being carried out by a variety of offices within DHHS and the Department of Education, including the National Institute of Mental Health, the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, the Administration for Children, Youth, and Families, the Office of Adolescent Pregnancy Programs, the Bureau of Health Education, and the Office of Maternal and Child Health. As noted earlier, there is wide variation not only in subject matter but in approach.

Coordination of health instruction, health services, and food programs has been difficult to accomplish because of the traditional separation among eductors, health professionals, and nutritionists at all levels. There are at least a dozen Federal agencies supporting some aspect of school health, with little coordination or joint planning among those agencies, or between them and the States, who provide an estimated $300 million annually for school health activities.

The numerous curricula developed for adolescents in the school setting have had limited evaluation, particularly in measuring subsequent behavioral changes. Their successes and failures need to be examined so that professionals from education and the social sciences can determine which approaches show the most promise. The extent to which particular methods are effective with such issues as food habits, drinking and drug use, accidents, pregnancy among young teenagers, dropping out of school, and so forth is of major interest.

The Panel supports a unified, comprehensive approach to curriculum development and technical assistance to State and local authorities for health promotion activities. Acknowledging that the Departments of Education, Health and Human Services, and Agriculture all have a legitimate and important stake in school-based health promotion activities, we nonetheless believe it is appropiate that there be strong coordination of these efforts at the Federal level, to avoid duplication of effort and assure that learning is shared regarding program effectiveness.

The principal obstacle to such coordination at present, we believe, is the absence of a strong health education focus in the Department of Education, to complement the efforts of program managers in DHHS and USDA. The Department of Education now has an Office of Comprehensive School Health, but this office remains skeletal because the School Health Education Program (P.L. 95-561, Part 1) has not yet been adequately funded.

We therefore recommend that *Federal authorities strengthen their commitment to leadership in health education by taking the following steps:*

- Appropriation of adequate funding for the School Health Education Program (P.L. 95–561, Part 1), which provides for State and local education agencies to establish demonstration and pilot projects in comprehensive school health education.
- Increased support for the Office of Comprehensive School Health, so that adequate technical assistance can be provided to State and local education agencies, including the dissemination of successful health instruction curricula. Special emphasis should be given to familiarizing school personnel with effective programs for adolescents.
- Strong interagency coordination between the Federal Office of Comprehensive School Health in the Education Department and relevant counterpart offices in the Departments of Agriculture and Health and Human Services.
- The provision of incentives for State and regional education agencies to employ professionals with expertise in health education to give leadership in planning, coordinate teacher training

and curriculum dissemination, stimulate extracurricular programs, and assure parent involvement in local programs.

- Strengthening of health education components in Head Start programs and other federally supported preschool programs, through regulations, guidelines, dissemination of model curricula, and project monitoring, including emphasis on the involvement of parents.

Television

As we have noted, the mass media, and particularly television, have a tremendous potential to influence health. We believe that the Nation should be concerned about the effects of television from two standpoints—first that it do no harm, and second that its power be used to improve health-related behavior.

There is widespread agreement on the need to limit or at least counteract the negative effects of advertising and certain program content viewed primarily by young children. But disagreement continues regarding the degree of protection needed and the choice of methods. There are a number of methods that can be used to change television approaches, including complete and partial bans on certain types of advertising or behavior shown on programs; limitations on particular promotional techniques or behaviors; limitations on the number of commercials for given types of products; health warnings within the context of a given commercial; counteradvertising; and modeling of positive behaviors.

The advantages and disadvantages of these alternative strategies have been discussed by the staff of the Federal Trade Commission in the context of the proposed "Children's Advertising Rule" (*37*) and by the Federal Communications Commission (*38*). Both of the Commissions have concluded that while bans are remedies of last resort, the other alternatives are less likely to be effective in the case of young children. Other evidence suggests that adherence to the Broadcaster's Code has been disappointing. Militating against the use of bans, however, are constitutional questions and a history of *caveat emptor*.

The Panel does not possess the expertise to decide whether a ban on certain forms of television advertising or content is appropriate. We do, however, see the continuing need for a Federal regulatory presence with the power to enact such a ban should evidence of its importance be compelling.

Counteradvertising can provide supplemental nutritional, safety, and other health information. The major test of the effects of counteradvertising occurred during 1967–70 when the Federal Communications Commission's Fairness Doctrine led to $60 million worth of free television time in one year for antismoking campaigns to counter cigarette advertising. Although there was four times as much advertising for cigarettes as against them, there was a decline in per capita cigarette sales in the United States (*39*). Consumption increased again after both cigarette advertising and most antismoking messages were removed from television (*40*). The deterrent effect was less strong among adolescents, perhaps because the antismoking messages concentrated on health consequences only and did not appeal to attractiveness—the more salient motive for this age group.

The Panel also concludes that regardless of how many special children's programs are produced with private or public support, efforts must continue to assure that an appropriate proportion of the routine programming of all major television stations is of interest and benefit to children. Although some segments of the population are well served by the broadcasting system, the children's market is dramatically underserved. The FCC believes that there is considerable demand for and benefit to society from age-specific educational programming, but that this demand goes unfulfilled and the benefit goes unrealized due to children's limited appeal to the advertiser and the limited number of broadcast outlets.

In addition to these approaches, there are several other important avenues of health protection in television viewing. These include cable channels designed explicitly for children, with no controversial advertising or violent content; the fostering of critical viewing skills in children; and special efforts to create alternatives to television viewing, especially for disadvantaged children in neighborhoods with few recreational facilities or organized activities. These are discussed fully in one of the Panel's commissioned background papers (*41*).

In summary, the Panel recommends that *further national effort be devoted to countering media pressures on children, adolescents, and pregnant women to adopt behaviors deleterious to their health. Parents, communities, and advocacy groups should take the following steps:*

- Continue and broaden the dialogue with national television networks regarding commercial advertising, programming balance, and the modeling of health-related behaviors. Better and more systematic ways should be found to provide accurate information about health and health-related behavior to the creators of television entertainment programs.
- Actively assist in the development of critical viewing skills among children, particularly with regard to commercial advertisements.
- Encourage parents to monitor television viewing, to emphasize selective rather than continuous viewing, and to discuss programs and commercials with their children. Parents also should be encouraged and supported in providing alternatives to television viewing, including recreational opportunities.
- Promote the endorsement of healthful practices and products through the media by professional organizations and celebrities held in high esteem by children and adolescents.

Federal and State authorities and private foundations should support efforts to strengthen the role of television in promoting maternal and child health. In particular, public and private policymakers should support:

- Increased research on the effects of television on children, including efforts to analyze network and local programming. Periodic national reports should be financed by the Department of Health and Human Services and the National Institute of

Education on the content and behaviors enacted in programs and advertising directed at children.

- Adequate programming for children as one of the criteria for license renewal of television stations.
- Reestablished authority of the Federal Trade Commission to investigate the fairness of television advertising and program content in their effects on children and to promulgate regulations in regard to these matters whenever appropriate.
- Continuation of high quality educational programs with major health components, and development of new programs with Federal support.
- More health promoting public service announcements during children's and adolescents' "prime time" (e.g., Saturday morning and during after-school and early evening hours).
- Media campaigns to provide information about special risks to pregnant women of smoking, drinking, and improper drug use.

Television can be a potent force for health promotion, as exemplified by *Sesame Street*, the *Electric Company*, and other programs which function as good alternatives to programs with objectionable advertising content. But belief in the power of television without consideration of its limitations also has led to some expensive failures.

In reviewing the evidence on education via television, the Panel concludes that the production of high quality programs for a large number of schools and other local agencies that would never be able to afford them is a legitimate part of government health education activities, but given the magnitude of these expenditures, continuing research and outcome evaluations ought to be required.

The uses of television are expected to change as package programming, video discs and cable television become common. These alternate systems are much less expensive and provide a greater opportunity than broadcast television to reach specific populations, and they are also easier to combine with other educational methods. These avenues need to be explored in the future as well as programming for private and public broadcast television.

DHHS is in the process of redefining its role as a "wholesaler" of health information. This function is broader than simply deciding what messages should be presented via television, or considering the best means for communicating via other intermediary or "access" groups, such as health care institutions, labor unions, PTA's, and community organizations. Federal support is being seen as a way to build consensus, reach high-risk groups, and assure concerted action. The role of television as a part of this large process, and coordination of television messages with those communicated elsewhere, is an important matter which deserves further impetus. Attempts to promote good health via television can be substantially strengthened by a broad and coordinated Federal strategy involving careful definition of messages for particular groups—including children, adolescents, and pregnant women—and multiple means for conveying these messages to the groups who need to absorb them.

In summary, *the Panel recommends a strengthening of both private and public support for health-promotion activities via television.* At a minimum these should include:

- Continued support for high quality educational programs with major health components, and development of new programs under Federal support.
- Sponsorship of further health-promoting public service announcements for children, youth and pregnant women, targeted to prime time (including Saturday morning) and to after-school hours.
- A vigorous campaign to produce special health-related messages for particular groups of children, teenagers and pregnant women at risk, with integrated strategies for dissemination via television, as well as radio and the written media, simultaneous with dissemination via health care providers and schools.

The Workplace and the Community

Among the most significant changes in American life, noted earlier in the report, is the dramatic increase in numbers of women in the workplace, including large numbers of mothers. This change makes the workplace a more opportune site than ever before for providing family planning services, prenatal care and counseling, and anticipatory guidance for parents. A significant number of corporations and government agencies have made serious efforts to assist their employees in these matters, as well as helping balance the demands of work and private life by offering flexible-time work arrangements, child care, and various support services to parents.

The Panel believes that these efforts are highly significant, and should be enlarged in the future. Accordingly, *we recommend that all private corporations and government agencies give explicit attention to the needs of their employees for family planning services, prenatal care, and other forms of support for parents.* Model programs such as those sponsored by the March of Dimes Birth Defects Foundation are one example of what can be done by way of counseling in the workplace.

Formal and informal community associations and groups also continue to be an important source of support for parents, families and young people. The community offers a scale and familiarity better suited to certain forms of education and counseling than larger institutional structures.

The wide variety of organizations and lay self-help groups to be found in most cities and towns—including religious groups, the Boy and Girl Scouts, Boys and Girls Clubs, 4-H Clubs, PTA's, Candlelighters, Parents Anonymous, women's health collectives, food cooperatives, and numerous other groups—attest to the vitality and usefulness of community organizations in our country. Many of these groups currently sponsor, or could sponsor, significant health promotion activities.

Such local groups are needed to interpret and adapt centrally produced health information that cannot be equally sensitive to the many variations of problems, concerns, circumstances, risks, values, and attitudes of a

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pluralistic community and society. Programs with a strong commitment to empowering individuals, families, and community groups should, therefore, be given a high priority. Broad involvement of families and individuals in solving their own problems is to be encouraged.

When larger social groups surrounding an individual exert a positive health influence it is much more likely that the individual or family unit will be able to adopt healthful behaviors. Importantly, when people work together they are more likely to be successful in bringing about needed changes in institutions and other resources that may expand individual options. Many strong informal family and community networks already exist and perform significant and positive health promotion roles. These should be preserved and strengthened, or created if they do not already exist.

To some degree, public authorities can foster attention to health-related behavioral issues by such groups. One example of federally provided incentive to positive action is the recent risk-reduction demonstration grant program of the Centers for Disease Control, which provides modest funding for community-based efforts in health promotion (*42*). But many types of voluntary and informal organizations are difficult to create or render more effective via public policy. Instead, they depend upon the initiative and energy of private citizens.

An important social network also has been created by agricultural extension agencies in many of the Nation's rural areas. Agricultural Extension has a unique and only partially realized potential for health education in rural communities. Its mission is education and community development to help people improve their social and economic well-being, and one of its five goals is family health. There is a cohesive, credible and well-staffed network of home demonstration agents and youth workers which in many States still reaches small farmers and others. Health programming has varied over the years. Recently there has been a resurgence of interest and activity, but funding is very limited. Most States have extension specialists working on health projects, and in the 1970's eight States (Arkansas, Louisiana, Pennsylvania, Ohio, Virginia, Maryland, Missouri, and Wisconsin) received special Federal funding for consumer health education. The Panel regards such efforts very favorably, and believes they should be enlarged in the future.

In summary, whether through self-sustaining efforts or with public support, *the Panel urges that voluntary associations and community agencies renew their efforts to promote appropriate community-based education for parents.* Education programs and activities in community settings should focus on a wide range of health promotion goals, and should not overlook:

- Widening the availability of informal support groups and networks for pregnant women, new parents, parents of chronically ill or handicapped children, parents involved in child abuse and neglect, and other groups of parents with strong common needs for education and support.
- Increasing the cooperation among private industry, local organizations, and the schools in order to introduce health-related

content to community activities of major relevance to adolescents, including recreational opportunities and job training.

- Further developing health education and counseling via the Cooperative Extension Program of the Department of Agriculture, to take full advantage of the network of agricultural extension workers in reaching rural families.

Such efforts should receive the full assistance of community health care providers, the schools, and civic leaders.

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CHAPTER 4

IMPROVING NUTRITION

Good nutrition is fundamental to human health, performance, and well-being at every age and stage of life. Not only is it a prerequisite for optimal growth and development, it is also essential for the promotion and maintenance of health, prevention and treatment of disease, and recovery and rehabilitation from illness.

The role of nutrition in extending the lifespan and improving the health of the American population in recent decades is increasingly well recognized. Scientific advances such as the discovery and elucidation of the role of vitamins and minerals; public health efforts such as improved sanitation; technological developments such as pasteurization, food fortification and enrichment; expansions of income maintenance and food assistance programs such as food stamps, school feeding programs and others; and improvements in agricultural production, marketing, and distribution have all made a difference in the health of Americans.

Mothers and children have, of course, shared in these advances and benefited from our increased awareness of the need for adequate and appropriate diet. Nonetheless, much remains to be done to improve the nutritional status and health of mothers and children, and indeed all individuals. In this regard, the Panel finds that at least four major considerations must be weighed.

First, the Panel believes that the major role that nutrition plays in health has not been adequately recognized by the health community generally, including those whose principal focus is maternal and child health. Most recent reports on maternal and child health give scant attention to nutrition, and many programs providing health services and health education to mothers and children do not adequately cover nutrition issues. We find this neglect exceedingly misguided. In our view, nutrition is a major, not marginal, component of efforts to promote health and prevent disease in this population as in all age groups. Therefore, advocates of improved maternal and child health should attend carefully to issues of nutrition along with their more usual focus on, for example, health services.

Second, it is the Panel's view that national policies to promote adequate nutrition should relate to all income strata and ethnic groups and not focus solely on selected groups, because nutrition problems are not restricted to low-income or other specific groups in the population. In the [illegible]t, publicly financed nutrition services and support have focused primarily on those with demonstrated vulnerabilities—the poor, the ill, and the handicapped. Such an approach may have been appropriate for a health system directed at remediation. However, it is wholly inadequate for a health system that should focus more intently on promotion of health and prevention of disease. We must not abandon our commitment to individuals and groups who are at risk of undernutrition because of economic, social, or physiological disadvantage. But we can no longer afford to ignore nutritional problems common to all families and children.

Third, it is apparent that strategies to improve nutritional status must be designed to accommodate a new profile of nutrition-related problems that differs significantly from that of two or three decades ago. While there are still some who lack adequate food and suffer from malnutrition, starvation and gross nutritional deficiency diseases such as rickets and endemic goiter are no longer the major problems they once were. Today's nutrition problems are more likely to be related to overconsumption and imbalances in the types and amounts of foods consumed, and to exposure to an expanding variety of food additives and contaminants. The leading causes of death and disability for adults today include cancer, heart disease, and stroke—each of which may, to a greater or lesser extent, have roots in dietary patterns.

Fourth, the social and economic environment that influences both our use of foods and the nature of food substances themselves has changed dramatically in recent decades. Changing lifestyles, new food choices, technological and economic transformations in our food system, and related developments have produced a new "nutrition environment" which must be taken into account as we shape nutrition-related policies and programs.

Various sections of this chapter develop these four themes more fully and outline a set of actions to improve the nutritional status of mothers and children. Such strategies should be major components of national health and nutrition policies focused on this important population.

THE SIGNIFICANCE OF NUTRITION FOR HEALTH

In the sections below, three aspects of the relationship between nutrition and health are noted: the role of nutrition in normal growth and development; special nutrition issues in high-risk groups; and the relationship of diet to selected diseases.

Normal Growth and Development

An appropriate, balanced diet is important for health at all life stages, and is essential for women in the childbearing years, pregnant women, mothers who are breast feeding, infants, children, and adolescents.

Maternity care begins long before pregnancy in measures aimed at promoting the health and well-being of the young people who are potential parents. There is evidence that a woman's total life nutritional experience can have a significant impact on her reproductive performance and health. Women who enter pregnancy undernourished or who fail to gain adequate weight during pregnancy are at greater risk of having low-birth-weight babies. The rapid physiological changes of pregnancy along with other pressures often makes it difficult to correct longstanding nutritional deficiencies during the relatively brief time span of pregnancy itself. Health care programs including family planning services that care for women before and between pregnancies have a unique opportunity to identify women with nutritional or metabolic conditions that require correction, and to provide nutritional counseling to improve the nutritional status of women with poor dietary habits.

The relationship between maternal nutrition and pregnancy outcome has been the subject of numerous studies (*1*). Growth rates during intrauterine life are the most rapid of any time in life and depend in large part on maternally supplied nutrients. The rapid growth occurring during pregnancy requires an extra intake of calories—as much as a 20-percent increase—as well as more protein, vitamins, and minerals. There is considerable evidence (*2, 3*) that the nutritional health of the woman and her diet during pregnancy influence her weight gain, which has in turn been demonstrated to have a relationship to infant birth weight. Low-birth-weight infants have higher mortality rates and are more likely to suffer from physical and mental handicapping conditions. Nutrition-related factors that increase the risk of low birth weight and birth defects include alcohol consumption, which may replace nutritious food in the diet, and smoking, which may decrease appetite. Other factors such as limited money for food, unusual diets, and lack of knowledge and skill in adjusting the quantity and quality of the diet to meet the needs of pregnancy may have an impact on the nutritional status of the pregnant woman and affect the outcome of pregnancy.

Adequate nutrition is particularly important for women who breast feed. Lactation increases maternal need for calories, protein, and certain minerals and vitamins. Lactation in the absence of adequate nutritional intake can be deleterious to maternal health, and when intake is severely restricted, there may be a decrease in milk production which in turn compromises infant nutrition.

Although severe malnutrition is a leading cause of infant and child mortality and morbidity in the world, such cases are now rare in the United States. When they do occur, they are apt to be related to disease conditions such as chronic infection or malabsorption; to social pathology such as child neglect or abuse; or to unusual dietary practices. Recent surveys (*4, 5*) have indicated, however, that poor nutritional status, especially iron deficiency, does exist in some groups of the population, usually those of lower socioeconomic status. Infants are among the most nutritionally vulnerable of all age groups. Their accelerated growth and development and their greater nutrient requirements for size necessitate attention to their nutrition and feeding. Yet on the whole, infants as a group appear to have fewer nutritional problems than do preschoolers and other children.

Because feeding practices established in infancy can have an impact on long-term health, early detection and prevention of nutritional problems and initiation of sound feeding practices are important. Increasing appreciation of the nutritional, immunological, and psychological advantages of breast feeding and heightened concern about overfeeding in infancy have led to some recent changes in infant feeding practices. The downward trend in breast feeding which had occurred since the 1950's appears to have been reversed in the early 1970's. However, the practice of breast feeding is not increasing at the same rate in all populations. Nearly twice as many babies born to white mothers are breast fed compared to blacks, and breast-feeding rates are much lower among women with less than 12 years of education. Despite the promotion of breast feeding by such authoritative groups as the American Academy of Pediatrics, only 35 percent of all babies were breast fed in 1975 and such feeding ended by 3 months of age for the majority rather than extending for the longer period recommended (*6*, *7*).

During the preschool period, the rate of children's growth has slowed and their nutritional requirements for body size are less than during infancy. Thus they usually want and eat relatively less food. Other characteristics that affect the nutrition of preschool children are their increasing desire for independence and control over their environment, their immature self-feeding skills, and their periodic refusal to accept more than a limited variety of foods. Studies and surveys (*4*, *5*) have indicated that the major nutrition-related problems in this age group are iron deficiency anemia, mild retardation in physical growth, obesity, and dental caries. The 1971–73 Health and Nutrition Examination Survey I (HANES I) data indicated that about 5 percent of white preschool children and over 8 percent of black preschool children had low hemoglobin levels. Iron intake was below recommended daily allowance for about 95 percent of children 1–3 years of age, regardless of income. While not representative of the entire population, over 12 percent of the children seen in public clinics (generally low-income children) in 1976 showed some evidence of stunting of linear growth. Findings from other surveys, however, indicate that underweight and stunted growth are not widespread among American children as a whole. Indeed, obesity, or habits that could later lead to obesity, are more urgent nutrition-related problems for the preschool child. A complex problem involving many genetic and environmental factors, obesity in childhood can create serious long-term social problems and problems of adjustment and can have serious consequences for long-term health status.

Dental caries is another nutrition-related problem which affects large numbers of young children. Some estimate that 40–50 percent of 3–4-year-old children have dental caries (*8*). Research confirms a positive correlation between the amount and frequency of sweets consumed and the prevalence of dental caries.

Some parents depend on day care providers to supply a large proportion of the food consumed by infants and toddlers 5 days a week. Some preschool children in day care or other group care settings receive meals and snacks there that contribute 75–80 percent of their nutrient intake, which suggests that careful attention should be given to the quality of the food provided in such facilities. There are many service programs for preschool children and their families which offer opportunities for early detection of nutrition problems, as well as prevention through development of sound feeding practices. Every effort should be made to capitalize on these.

Nutritional needs of school-age children and adolescents are of concern because of their continuing growth. Trends in food consumption of the U.S. population show that children consume a substantial portion (38 percent) of their calories from fat and eat more highly sweetened foods than other age groups. Although data on the percent of calories from sugar in children's diets are not yet available, it is known that children and teenagers consume the most commonly eaten sweetened foods—soft drinks, cookies, desserts, and candy—both more frequently and in larger quantities than adults (*9*).

Nutritional needs in adolescence are greatly increased since the growth spurt experienced by such young people is exceeded only by that of the developing fetus and infant in the first year of life. Differences in the duration, timing, and extent of growth at adolescence largely account for the differences in nutritional need between males and females in this age group. Some of the nutritional problems noted above, such as obesity and dental caries, continue in this age group, while diseases affecting the adult population also begin to be seen in adolescence. For example, physical examinations of adolescents indicate that 5 percent have significant cardiovascular problems and that 8 percent of adolescent males and 4 percent of adolescent females have elevated blood pressure. Fifty-five percent of adolescents show some sign of tooth decay, and obesity is fairly common. Anorexia nervosa is also an increasing problem with this age group as is underweight, particularly for girls (*10*).

Some of these problems are related to adolescents' concern with identity formation, sexual maturation, and increasing independence, all of which have implications for nutrition. Many adolescents are involved in sports, and some current practices such as weight reduction or gain to meet requirements for certain sports, unusual diets for "quick energy," and crash diets for weight reduction may adversely affect the health and well-being of the growing adolescent.

Nutrition Issues in High-Risk Groups

There are some mothers and children who, by virtue of such factors as socioeconomic and minority status, age, and cultural background, are at special nutritional risk. These groups are vulnerable not only to the nutrition-related problems that beset the entire population, such as dental caries, obesity, and iron deficiency anemia, but also to a host of others including low birth weight, growth retardation, and handicapping conditions. Other particularly vulnerable groups are those with physical or mental handicaps, chronic conditions or disease states which predispose them to both financial and nutritional stress. Social problems such as child neglect, drug and alcohol abuse, especially in teenagers, have potentially significant nutritional implications as well.

Of great concern are young pregnant adolescents who are at particular risk because the stress of pregnancy is superimposed upon that of adolescence. There is a higher likelihood of pre-eclampsia, anemia,

NUTRIENT INTAKES BELOW 1980 RECOMMENDED DIETARY ALLOWANCES

Average intake as percentage of 1980 RDA, spring 1977

Sex and age (years)	Protein	Calcium	Iron	Magnesium	Phosphorus	Vitamin A	Thiamin	Riboflavin	Niacin	Vitamin B_6	Vitamin B_{12}	Vitamin C
Males and females:												
Under 1												
1-2			■■■■									
3-5		■■	■■■	■						■		
6-8				■						■		
Males:												
9-11		■		■■						■		
12-14		■	■■	■■						■		
15-18		■	■	■■■						■		
19-22				■■						■■		
23-34				■■						■■		
35-50		■		■■						■■■		
51-64		■■		■■						■■■		
65-74		■		■■						■■■		
75 and over		■■		■■■						■■■■		
Females:												
9-11		■■	■	■■						■■		
12-14		■■■	■■■■	■■■	■					■■■		
15-18		■■■■	■■■■	■■■	■					■■■■		
19-22		■■■	■■■■	■■■■		■	■			■■■■		
23-34		■■■	■■■■	■■■			■			■■■■		
35-50		■■■■	■■■■	■■■						■■■■		
51-64		■■■■		■■■						■■■■		
65-74		■■■		■■■						■■■■		
75 and over		■■■		■■■						■■■■	■	

	100% RDA
■	90-99% RDA
■■	80-89% RDA
■■■	70-79% RDA
■■■■	Below 70% RDA

excessive or inadequate weight gain, and low birth weight in the pregnant adolescent. Adolescents are 30–50 percent more likely than older women to have low-birth-weight babies, and a baby born to an adolescent is two to three times more likely to die during the first year (*1*). As noted earlier, nutritional requirements for size for adolescent growth are higher than those of any other period of life except infancy, and pregnancy occurring during adolescence results in additional needs for calories and nutrients. Yet the adolescent period is frequently characterized by fad diets and nutrition-related problems which are often related to an overemphasis on slimness, to drug and alcohol abuse, limited money for basic necessities, and other such social and economic problems.

Another group of special concern is pregnant women with conditions such as hypertension, diabetes mellitus, heart disease and renal disease. These women are at increased risk of having complications of pregnancy and low-birth-weight babies. Many of these diseases have nutritional implications and require expert dietary management and intervention. More women who were treated during their own infancy and childhood for inborn errors of metabolism, (e.g., phenylketonuria) are now bearing children. To prevent severe mental retardation in the infants of such women, dietary intervention is often required (*11*).

Many infants of low birth weight, with birth defects or other problems also have special feeding or nutritional needs after birth. For example, infants with inborn errors of metabolism may require specific dietary intervention shortly after birth to prevent serious complications, including mental retardation and death; similarly, infants with carbohydrate intolerances require early dietary modification to grow and develop normally. The estimated 6 percent of all newborns who are of low birth weight also require special care. The nutritional goal for the latter group is to support a rate of growth approximating that of the third trimester of intrauterine life, without imposing stress on the developing metabolic or excretory systems. Appropriate feeding of low-birth-weight infants is most important since this is a crucial period of development when inadequacies, excesses, or imbalances are most likely to lead to permanent problems.

Recent success in keeping alive some children who formerly would have died of such conditions as the complications of prematurity, severe malformations of the gastrointestinal tract, diabetes, or cystic fibrosis has also changed the face of the malnutrition seen today. It has increased the danger of malnutrition secondary to disease unless such children receive the special nutritional support or therapy they need.

Children with chronic illnesses and handicapping conditions frequently need therapeutic diets requiring very detailed and specific nutritional counseling and support. Diseases of this type include some forms of cancer, heart disease, juvenile diabetes and hypertension, renal disease, malabsorption, and cerebral palsy. Children with motor problems involving the central nervous system are also at risk for nutritional problems. At first, these children often have difficulty sucking and swallowing. As they develop, they have difficulty in controlling the head, trunk, and extremities. Overweight may result from inactivity or limited movement, which often makes it more difficult for a handicapped child to use crutches, braces, or artificial limbs.

Other groups at particular risk of dietary inadequacy are women and children in minority groups, including migrants, native Americans, Alaskan natives, and refugees. Low income is a major factor in such risk; others include certain culturally determined food habits which may be unsound, mobility and lack of adequate food storage and preparation facilities, language barriers, and social instability. Such characteristics can isolate these groups and decrease their ability to obtain needed food, health information, and services for themselves and their children. Such problems are especially acute for refugees and other foreign born individuals who face a difficult and prolonged adaptation to a new way of life (*12*).

Diet and Disease

The nutrition-related issues discussed in the preceding section are significant not only because of their general importance for growth and development and their special significance for high-risk groups, but also because some of the main health problems in America today have been linked to certain dietary patterns. Dietary habits begun in childhood may well increase the probability of developing certain chronic degenerative diseases later in life.

Obesity

Obesity, an excess of body fat, results from eating more food than the body uses for its basic energy needs and/or from expending less energy than supplied in the diet. Obesity is associated with an increased risk of high blood pressure, gallbladder disease, and adult onset diabetes, all of which are in turn associated with increased risks of heart disease and stroke. It also creates social, psychological, and economic hardships for many.

Obesity is widely prevalent in our society and its frequency appears to be increasing. It is probable that a trend toward obesity can be established early in life, and once established, childhood obesity tends to continue into adulthood, becoming increasingly resistant to treatment. The obese child, according to the Surgeon General, is three times more likely than other children to become an obese adult. In fact, one-third of all obese adults were overweight as children. Obesity in adults remains extremely difficult to treat successfully, with up to 95 percent of patients regaining some or all of the weight they have lost. For all these reasons, primary prevention is considered the most promising strategy of intervention.

American children 6–11 years old are exceedingly sedentary by world standards and probably even in comparison to the norms for past decades in this country. Obese children as a group are more sedentary than lean children, and even when active exert themselves less than other children. Few primary schools do much to remedy this situation. Some schools lack physical education entirely, while in others the bulk of time and attention is devoted to making the fit "fitter" rather than encouraging the unfit and the obese to participate more in physical activity programs within and outside of school. The most effective strategies for achieving and maintaining desirable weight in children appear to be based on combined changes in diet, activity patterns, and redirecting various social and emotional "cues" away from overeating and inactivity (*13, 14*).

Dental Caries

By age 11, the average American child has three decayed permanent teeth. By age 17, the average youth has eight to nine decayed, missing, or filled teeth. Untreated tooth decay leads to the loss of permanent teeth, which is disfiguring and can result in dietary and communication problems, and social and emotional difficulties.

In the past few decades it has been established that dental caries is a food-related disease. In general, the cariogenicity of the diet is due to its simple carbohydrate content and to the adhesiveness or retentiveness of these carbohydrate-containing foods. Epidemiological evidence indicates that population groups consuming high amounts of sugar suffer high levels of dental decay. However, the quantity of sugar is not the only important factor in dental caries. Frequency of consumption and time of ingestion are also critical factors in caries development. Foods high in sugar also differ in their cariogenicity. Candies and other items that contain very high concentrations of sugar account for only about 10 percent of all sucrose eaten in the United States and their damage to teeth depends more on their acidity than on their sucrose content. Soft drinks or starchy foods, on the other hand, account for almost three times as much sugar consumption and their role in caries production may be equal to or greater than that of high sugar candies. Snacking habits involving foods high in sugar are prevalent among children and adolescents, the age groups that are also the most susceptible to tooth decay (*13, 15*).

High Blood Pressure

High blood pressure is one of the most important risk factors for heart disease, stroke, and kidney failure. It is also one of the most common disorders of adults and possibly teenagers, affecting one of every six Americans. Rates of high blood pressure in our population increase with age, particularly for women. Blacks are twice as likely as whites to have high blood pressure, and it is more common in lower income and less educated groups.

Population and laboratory studies have implicated lifelong high levels of salt consumption as a contributing factor in the onset of high blood pressure in some susceptible populations. Groups that traditionally consume high levels of salt, such as the Japanese, demonstrate extremely high incidence. Those who consume very low levels of salt show little evidence of the disease and no increase in blood pressure with age. Other dietary factors implicated in high blood pressure are obesity and diets rich in fats. Weight control and lower fat diets or diets with equal portions of polyunsaturated and saturated fat have been shown to lower blood pressure in human subjects. Focusing specifically on these risks in children, it is significant that the total diets of many children are apparently excessive in saturated fat and salt (*13*).

Coronary Heart Disease

Heart disease is the leading cause of death among men over 40 years of age. Although it is one-third as common in premenopausal women, after menopause the incidence rises. While age-specific death rates from heart attacks have declined sharply in the last two decades, this disease still accounts for one-half of the mortality of American men. Nearly one-third of heart attacks occur before the age of 65.

No one factor has been directly shown to reduce the risk of heart attacks, but control of all known risk factors, including moderation in the levels of dietary fat, saturated fat, and cholesterol in the diet, are believed by many to be effective. Other risk factors include smoking, high blood pressure, diabetes mellitus, emotional stress, family history, and sedentary lifestyles. Populations with high consumption of dietary fat and cholesterol tend to have high blood cholesterol levels. The risk of heart attacks is greater among individuals in populations with high blood cholesterol compared with those in societies where people eat diets lower in fat and cholesterol and have lower blood levels of cholesterol.

There is consensus among medical experts that although the clinical effects of atherosclerosis are not usually apparent until midlife, the condition is often well advanced by the third decade of life, with early signs evident in the first decade. About 8 to 25 percent of adolescents have serum cholesterol levels above the desirable level. Therefore, it may be that primary prevention should begin in early childhood (*13, 15*), particularly for children whose parent(s) have had a heart attack at an early age (*16, 17*).

Cancer

Approximately one-fifth of all Americans die of cancer. The causes of cancer are complex and far from clear, but current evidence suggests that behavioral and environmental factors may play a primary role in its development. Epidemiologic and experimental data suggest the consumption of high-fat diets and diets low in dietary fiber may be implicated in development of some cancers, although more research is clearly needed on this issue (*13, 15*).

Diabetes

Diabetes affects up to 5 percent of the American population and appears to be increasing in prevalence. The disease is common in all affluent countries and rare in developing countries. For non-insulin-dependent (i.e., adult onset) diabetics, who comprise 90–95 percent of the diabetic population, the disease is associated with obesity, and can be controlled by weight reduction. Diabetics are known to be more susceptible to heart attacks than nondiabetics and to have elevated levels of serum lipids.

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Until recently, dietary advice to control adult onset diabetes has emphasized limitation of carbohydrate intake, particularly sugar. Now that the susceptibility of diabetics to coronary heart disease is recognized, along with their tendency to have elevated levels of serum lipids, dietary management emphasizes limitation of fat intake rather than the limitation of complex carbohydrates (e.g., starch and fiber), within a diet that stresses attainment and maintenance of desirable body weight (*13*).

THE NUTRITION ENVIRONMENT

Given the significance of nutrition for sustaining healthy growth and development in all groups including those in various high-risk situations, and our growing understanding of the relationship between diet and disease, interest in promoting good nutrition-related habits in all individuals is increasing. Determining how to do so, however, has become especially complicated and challenging due to a variety of social, economic, and technological changes that have transformed American society since World War II, and reshaped the food choices and habits of children and families.

One measure of social change with significant implications for nutrition is that the number of working women in the United States has doubled in the last 40 years, and the number of working mothers has risen tenfold. In 1979, U.S. Department of Labor figures showed that 45.4 percent of all women with children under 6 and 54.5 percent of women with children under 18 were working. Both percentages are expected to increase significantly in the next decade (*18*). Full schedules mean little time or energy to plan, shop for, and prepare family meals. The phenomenal growth in "convenience" and prepared foods reflects this, as does the huge growth in eating away from home, a roughly $67 billion business in 1979 (*19*). Between 1958 and 1978, sales in fast-food restaurants increased 305 percent; sales growth in other restaurants, although much smaller, was still a sizable 83 percent (*20*). One correlate of these changes has been a gradual shift in attitudes about eating. Surveys have shown a strong interest in nutrition, but new concepts of what constitutes a "balanced meal" or a "balanced diet" are emerging. A growing number find that food and meal patterns need to be more flexible to conform to faster paced and less structured lifestyles, and believe that a nutritious diet can be achieved by eating less traditional menus at any time of the day, rather than at three fixed meal periods.

As women join the labor force, household duties, including those related to food, are shared among family members. The role of the mother as "family food gatekeeper" has been circumscribed. It can no longer be assumed that she knows what the whole family eats, as children and adults alike now make more independent decisions about what, when, and where to eat. More men and children shop and cook, and families eat fewer meals together. Work and school cafeterias, day care centers, vending machines, and fast food outlets now provide many of the meals formerly eaten at home.

One clear measure of changing eating patterns is the high prevalence of eating away from home and snacking—both of which contribute significantly to total calories consumed daily. Studies of food consumption patterns show that for children who consumed food away from home, such food accounted for 35–40 percent of daily caloric intake. Approximately two-thirds of all children and teenagers report at least one snack in a 24-hour period. Snacks contribute about one-fifth of daily calories, equal to the caloric contribution of breakfast, but less than the recommendations for nutrients other than calories (*9*).

Various technological changes have also influenced American nutritional status significantly. People now stand at the end of a highly sophisticated food chain that to a large extent controls the nature and flow of food from farm to individual. Major changes in food technology have given us the capacity to mass produce everything from bread and cheese to frozen dinners and desserts, and to invent an enormous range of innovative food products. Such developments have given impetus to the growth of fast food and other restaurants, cafeterias, vending machines, airplane and train meal service—all of which depend on the efficiency and centralization of our food production sector and the sophistication of our new food technology. Consumers become acquainted with these new food products when eating out and, according to marketers, eventually demand and use them in the home.

In 1928, grocery stores offered an average of 867 items (*21*). The average supermarket now contains approximately 13,000 items (*22*). Agricultural and technological advances allow buyers to choose not only from basic commodities—vegetables, fruits, grains, meats, and dairy products—but also from a broad range of processed foods. It has been estimated that over half of the food Americans buy is now processed to some degree (*23*). A growing percentage of items in the grocery store are foods in which some of the naturally occurring nutrients may have been lost in the manufacturing process, while fat, salt, sugar, artificial flavors, colors, preservatives, stabilizers and texturizers may have been added.

As we move further away from the basic foodstuffs that have sustained our species historically, we must depend more on our knowledge of human biology and nutrition to tell us whether we are eating adequate and safe diets. Unfortunately, our knowledge is too imprecise and our science too young to provide this assurance; indeed, some have called our new food system the greatest human experiment ever performed by man on man. Government and private surveys in recent years have documented growing public concern and confusion about food safety and the nutritional adequacy of the present food supply (*24*). Many fear the effects from increased chemicals in processed foods and others are uncertain about the nutritional and other properties of processed foods. The exceptional growth in the "health food" industry in recent years, now an almost $2 billion industry, attests to the extent of such concerns (*22*).

A vast amount of nutrition-related information is now directed to the public—some of it accurate, much of it imprecise, if not wrong. The messages that Americans receive about food, diet, and health are as inconsistent as their sources are numerous. Traditionally, families depended on long-term experience with foods, including sensory cues, appearance, smell, and taste to guide food choices and to teach nutritional values to children. Now, people increasingly depend upon information provided by sources outside of the family—friends, grocers, doctors, teachers, ingredient lists, nutrition labeling, manufacturers' statements on packages and in advertisements, and Government policies and pronouncements—when making food decisions.

By far the most pervasive messenger, and the most heavily used by the food industry, is television. According to a National Science Foundation report, every year children watch approximately 20,000 television commercials for food products (*25*), most of them devoted to snack foods, soft drinks, and breakfast cereals. The industry spent $2.5 billion in 1978 to advertise its food products, 90 percent of which was allocated to television. This sum was more than twice that spent for automobile and gasoline advertising—the second largest user. For some groups, particularly the poor and those in rural areas, television may be the predominant source of nutrition information. A recent issue of USDA's *National Food Review* analyzed mass media food advertising by types of food, and found that:

> Highly processed foods account for a large part of total media advertising. About $280 million was spent on soft drinks alone, accounting for about 13.5 percent of media advertising for the food system in 1978. Perishables or relatively unprocessed foods take a very small portion of advertising expenditures. The lowest advertising rate is for unprocessed meats, poultry, fresh eggs, dairy products, and fruits and vegetables. Combined advertising in the six media (spot television, network television, network radio, magazines, supplements, and outdoor advertising) for these products in 1978 was about $140 million, or *half* what was spent on soft drinks (*26*).

Complicating the issue of food choice further, inflation takes an increasingly large bite out of family paychecks. A 1980 Yankelovich, Skelly and White, Inc. survey reported that families are struggling hard to maintain their interest in and commitment to sound nutrition. But food costs are forcing them to make many changes in their food shopping, preparation, and eating habits—and not always in the direction of improved quality. The pressure of food cost inflation is felt by all sectors of society, but, in the words of the survey report, "especially by the parents of the Nation's children" (*24*). For the poor in particular, food cost escalation raises the basic cost of living. Also, the gradual withdrawal of competitive supermarkets from the inner city means that the urban poor have an increasingly limited access to quality food at affordable prices, and must depend on small corner grocery stores that stock only a limited supply of food items (*27*).

By many indications, people have a strong and continuing interest in nutrition and want to feed themselves and their families well. But to do so has become increasingly difficult given our new nutrition environment. A very sophisticated and broad approach to enhancing dietary quality will be required if families are to provide the best possible foods for their children, and if children and adults are to develop and maintain health promoting lifelong eating habits in today's fast changing society.

STRATEGIES FOR IMPROVEMENT

Cognizant of the nutrition issues discussed in the preceding sections, the Panel has focused on four approaches to improving the nutritional status of mothers and children. These are to increase nutrition-related information and education, to strengthen the role of nutrition services in health care programs both public and private, to expand and improve the various public feeding programs, and to focus research on a set of specific nutrition issues. We do not suggest that these are the only strategies available. We have not, for example, addressed ourselves to such issues as regulation of the food industry, standards of food quality and safety, and other similar matters that must also be considered. Those itemized below, however, seem the most significant from the perspective of the health community. In the aggregate, they may be regarded as major components of a more comprehensive national nutrition policy focused on mothers and children.

Information and Education

A primary strategy for improving the nutritional status of mothers and children is information and education covering many topics and provided through many sources. Simply put, *if nutrition is to become a central component of efforts to improve maternal and child health, there must be a commitment in all appropriate sectors—the health system, schools, the media, private industry and Government—to educate the Nation more adequately about health-promoting and risk-reducing diets. Every effort should be made to help parents and children understand what constitutes diets that avoid deficiencies, imbalances, excesses of nutrients or energy, and minimize dietary risk factors for disease.*

Regardless of the source, the content of nutrition education pertinent to mothers and children needs to be broadened to incorporate the newer concepts of health-promoting diets. The education must be consistent, practical and useful, and of sufficient depth and breadth to serve as a basis for sustaining eating habits that promote health over the full life span. The nutrition message should be based on a recognition of the role of nutrition in lifelong health and of the individual's responsibility for promotion and maintenance of his or her own health. It should be varied and tailored to meet the specific needs of specific audiences, but the basic content must be consistent and coordinated. No single message or nutritional guideline will meet all of the public's needs. Instead, nutrition education must face the complex task of presenting the best currently available information on nutrition and health given different stages of scientific certainty, and of presenting guidance oriented to the practical realities of culture, lifestyle and available foods.

With these general perspectives in mind, we urge *that the Federal Government take a leadership role in informing and educating the Nation about a wide range of nutrition issues. Norms for appropriate nutrition should be developed, routinely updated, and vigorously disseminated by Federal authorities for the benefit of all Americans, including children and pregnant women in particular.* An example of the Government fulfilling just this function was the release in 1980 of "Nutrition and Your Health: Dietary Guidelines for Americans," developed jointly by DHHS and USDA (*28*). The Panel finds the guidelines to be prudent advice to Americans about nutritionally sound diets and applicable to the needs of children and pregnant women. Particularly in light of the information presented earlier regarding the relationship of diet to selected health problems and diseases, the Panel calls special attention to the recommendations to:

- Maintain ideal weight
- Avoid too much sugar
- Avoid too much sodium (salt)
- Avoid too much fat, saturated fat, and cholesterol

We also call attention to the strong advocacy in the guidelines of breast feeding, unless there are contraindications; the value of delaying the introduction of solids until an infant is 3–6 months old; the cautionary messages directed at pregnant women regarding alcohol use; and the general need of both pregnant and lactating women for high-quality diets that contain extra calories and more of many nutrients.

Many of these basic concepts are particularly important to convey to school-age children. In chapter 3, the broad issue of health education is discussed in depth. Here we would only add a *recommendation that comprehensive school-based health education programs include a major emphasis on nutrition. We caution, however, that to do so will in many instances require the development of more adequate nutrition education curricula and materials.* While some agencies and organizations have been concerned with nutrition education, they often have generated teaching materials or program guidance of only limited effectiveness. The emerging consensus reflected in several recent reports is that nutrition education programs and materials need to be more comprehensive, carefully designed, and in step with current nutrition information. New materials should be based on current knowledge about nutrition, be carefully designed for different developmental stages, include appropriate emphasis on peer and parent roles in nutrition-related behavior, and, in general, be designed with the new nutrition environment in mind. They should also be developed in light of the sound and comprehensive set of guidelines for nutrition education contained in the 1979 National Conference on Nutrition Education recommendations (*29*). *We recommend that the relevant offices of USDA, DHHS, and the Department of Education, the States, and private foundations collaborate on the development of nutrition education curricula for school-age children and adolescents, and that such efforts include adequate evaluation of model curricula.*

School-based nutrition education is not sufficient, however. The Panel is also deeply concerned that the media increase its efforts to promote sound nutrition-related habits. In comparison with the billions spent each year on food advertising, little money is spent on nutrition education. This imbalance is strikingly evident in children's television programing which includes so many food-related advertisements that are widely regarded as health-compromising. This issue is discussed more fully in chapter 3.

The Federal involvement in nutrition education programs is also significant and a major means by which nutrition information and education can be promoted. Currently, there are approximately 30 programs in 11 Government agencies that have an identifiable nutrition education component; of these, 22 involve specific child nutrition education activities. Despite a history of involvement in programs of nutrition education, the Federal Government has not been notably successful in this field. Message content and techniques for communicating nutrition information have been criticized in detail by the General Accounting Office (*30*) and the 1979 National Conference on Nutrition Education (*29*). The major problems identified include sluggish Federal mechanisms for achieving a working consensus on nutrition guidelines, inefficiencies in arriving at consensus on appropriate messages and special emphases for target groups, and problems in defining and reaching target groups.

There are two federally funded programs specifically designed for nutrition education. The Expanded Food and Nutrition Education Program (EFNEP) and the Nutrition Education and Training (NET) program. EFNEP is a service of USDA directed at low-income families. The program was inaugurated in 1968 to provide food and nutrition education to homemakers with young children via trained indigenous nutrition aides. These paraprofessionals, who are supervised by county Cooperative Extension Home Economists, develop a one-to-one relationship with disadvantaged homemakers enrolled in the program at the county level. During the 1970's, EFNEP expanded rapidly to include all 50 States and Puerto Rico, reaching its maximum size by 1973. Currently more than 300,000 homemakers are enrolled in the EFNEP, which employs about 4,000 paraprofessional nutrition aides. The annual program budget, which for FY 79 was approximately $50 million, is distributed to Cooperative State Extension Services according to a poverty population formula. EFNEP has reached only a small proportion of the total low-income population during the past decade. EFNEP families comprise only 3 percent of the more than 6 million households in the Food Stamp program. EFNEP has tried to rectify the low participation rates of food stamp households by working closely over the past year with Food Stamp programs; sixteen pilot projects were funded in 1979–80 to identify ways of increasing participation of food stamp households in the EFNEP. In addition, the pilot projects are testing alternate ways of delivering EFNEP services. Rather than relying exclusively on nutrition education on a one-to-one or door-to-door basis, use of multi-media approaches is being tested.

NET was established in 1977 by P.L. 95–166, an amendment to the 1966 Child Nutrition Act. Its legislated purpose is "to encourage effective dissemination of scientifically valid information to children participating or eligible to participate in school lunch and related child nutrition programs." NET funds are distributed through State education agencies to local schools and districts for use in training teachers and school food service personnel and to conduct nutrition education activities that fully utilize both the school food service facilities and the classroom. The NET program is intended to help children learn to apply principles of good nutrition in their daily lives. Better understanding of good nutrition and its relationship to health is expected to increase the acceptance of nutritious foods provided through school food service, with a concomitant decrease in food waste. In FY 1980 the NET program reached 3.5 million children, and had a budget of $20 million. Evaluation studies are now underway to determine the results and achievements of the program.

Without prejudging the relative merits of EFNEP or NET, especially since various pilot studies and evaluations are underway to strengthen the programs, the Panel nonetheless *urges the leaders of both EFNEP and NET to design these programs in a way that is consistent with the principles of nutrition-related information and education outlined at the beginning of this section.*

Before leaving the topic of information and education, the Panel wishes to call special attention to the fact that all the strategies mentioned thus far—whether in schools, the media, or public and private health care programs—concentrate primarily on encouraging changes in the behavior of individuals. This, in our view, is only a portion of the remedy. We call equal attention to the role of institutions in influencing the nutrition-related practices of individuals, and the complex relationship of individual behavior and social influences in this regard. A particularly important example of this interplay relates to the practice of breast feeding. As previously noted, breast feeding is of great nutritional and immunological significance to the developing infant, and is also believed to enhance mother-infant attachment. The Panel concurs with the American Academy of Pediatrics (AAP), that "breast feeding should be strongly recommended for full-term infants, except in the few instances where specific contraindications exist" (*31*). We also share the concern that breast feeding is not as widely practiced as it might be. To increase the incidence and duration of breast feeding, however, we caution that it is not enough simply to increase the information and education about this issue. We suggest that broader social influences and institutions affect the choices women make about how to nourish their infants. *To increase breast feeding, employers, health care providers, the health care system generally, and other institutions should take steps to encourage breast feeding and support mothers who choose to breast feed and are able to do so.* For example, of the several suggestions made by the AAP to increase breast feeding, many focus on institutional changes. With regard to ways to change aspects of the health care system specifically to support breast feeding, they state:

> The routine in many hospitals makes breast feeding difficult; therefore, efforts should be made to change obstetrical ward and neonatal unit practices to increase the opportunity for successful lactation. Changes may include the following:
>
> (1) Decrease the amount of sedation and/or anesthesia given to

the mother during labor and delivery because large amounts can impair suckling in the infant.

(2) Avoid separation of the mother from her infant during the first 24 hours.

(3) Breast-feed infants on an 'on demand' schedule rather than on a rigid 3- to 4-hour schedule, and discourage routine supplementary formula feedings.

(4) Reappraise physical facilities to provide easy access of the mother to her infant. Rooming-in of mother and infant is important to successful lactation.

(5) Attitudes and practices in prenatal clinics and in maternity wards should encourage a climate which favors breast-feeding. The staff should include nurses and other personnel who are not only favorably disposed toward breast-feeding but also knowledgeable and skilled in the art (*31*).

We would add that employers should recognize the special needs of mothers with young infants and structure schedules and hours to facilitate breast feeding; and that education about breast feeding should be presented in the public media, and included in the curricula of health professionals and in school-based health education programs; and that various backup services to support breast-feeding mothers should be developed and built into the health care services available to women of reproductive age.

Another example of the importance of institutions in the area of nutrition relates to the role of supermarkets, restaurants, and other marketers of food in ensuring that an adequate selection of nutritious foods is available and in sharing the responsibility for educating and informing the public about sound nutrition. Even the most "educated and informed" consumer will have difficulty in maintaining a health-enhancing diet if the foods readily available in the course of daily life are of poor nutritional quality. We recognize that the forces that shape the nature and availability of foods are complex and not amenable to simple analysis. Nonetheless, as a guiding principle, *we urge that major manufacturers, distributors and marketers of food recognize the powerful role that their practices and policies play in shaping the nutrition-related preferences of the American public and children in particular, and undertake steps to not only ensure that nutritious foods are widely available, but also to help in educating the public about the importance and the components of a nutritious diet.* For example:

- Vending machines—especially in schools—should provide a variety of nutritious foods, such as fresh fruit, milk, and fruit juices, and not just the usual fare of candy, salty snacks, and soft drinks.
- Supermarkets should use various strategies—such as posters, pamphlets, and sample recipes and menus—to educate their customers about sound nutrition principles.
- Restaurants and fast food chains should ensure that the foods they offer include an adequate number that are of high nutritional quality.

Nutrition in Health Care Services

A second means for improving the nutritional status of mothers and children is to increase the extent to which nutrition services are integrated into health care services. Such nutrition services include screening and assessment to determine nutritional status and to identify nutritional needs and problems; counseling to help individuals adjust daily activity and food consumption to meet health needs; nutrition education to enable parents, other child caretakers, and children themselves to make informed decisions about food; referral to food programs and other types of community assistance as needed to maintain an adequate diet; followup services as appropriate to ensure that dietary recommendations are implemented and reinforced. Many women and children will also need help with problems such as home and money management and use of various community support services and resources.

Although the need for and value of such services as an integral part of health care has been recognized by many providers and agencies in both the public and private sectors, there are still far too many mothers and children who do not receive appropriate and necessary nutrition services. The reasons for this neglect include, in our view, the fact that nutrition services are financed only to a limited extent, if at all, by many public and private health care financing systems; wide variations in the knowledge and skills of health professionals regarding nutrition; and the limited availability of nutrition professionals in the health care sectors. Over time, however, such barriers are surmountable, leading the *Panel to recommend as a general principle that the policies of both the public and private health care sectors should ensure that nutrition services become an integral part of health services for mothers and children, directed both at health promotion and disease prevention, and at treatment and rehabilitation.*

Within this broad framework, the Panel calls specific attention to the place of nutrition services in the setting in which so much of this Nation's pediatric and maternity care is delivered—the office of the private practitioner working alone or in a group practice. As we discuss in chapter 6, it is essential for such practitioners to have strong links to various services that cannot typically be provided in any single office setting but whose availability is essential if comprehensive care is to be offered. Nutrition services are a prime example. *We urge that health care providers give specific consideration to their patients' nutrition-related needs as part of the full range of health services offered, and that they organize their practices so that they are closely linked to nutrition services and professionals in their community in order to make appropriate referrals to meet their patients' nutritional needs.*

We realize, however, that even those health care providers who wish to give increased attention to nutrition issues and to teach children and families about healthful nutrition practices may have trouble doing so because their own training did not include adequate attention to nutrition. Historically, pediatricians have been taught to include information about diet and nutrition as part of routine well-baby care during the first year or so of life. However, after that, physicians usually do not counsel parents and children about nutrition. Too often, if the child's height and weight fall within normal limits on a growth curve, little is said about the adequacy or the quality of diet. Similarly, parents are infrequently provided with sufficient guidance to help children who are obese or too slender, or to manage the dietary problems associated with certain chronic illnesses. To ease this problem, *the Panel urges that medical school training, residency training for primary care practitioners and training for all other health professionals, particularly nurses, who intend to work in a primary care setting include instruction in: basic principles of nutrition, especially as such principles pertain to key developmental stages such as pregnancy, lactation and infancy; food choice and eating habits of children and their parents; cultural variations in food choices; and strategies to help both parents and children change and improve their nutrition-related habits.*

Similarly, and in recognition of the relatively untapped contribution that other types of professionals may make in the health area, *we encourage training programs for social service personnel, teachers, day care staff, and other appropriate professionals who come in frequent contact with pregnant women, children, and families to include basic training and continuing education in nutrition commensurate with their role and responsibility for nutritional care.*

Such steps should be accompanied by others addressed to selected financing issues. In the Panel's view, the lack of financial support for nutrition services in private and public health care programs is a major barrier to expanding the accessibility and quality of nutrition care available to mothers and children. An especially unfortunate example of such financing inadequacies is that the model of reimbursement of most health care services, Title XVIII (Medicare) of the Social Security Act, does not provide reimbursement for nutrition services such as nutrition counseling as a home health service. Another example relates to the special problems that arise when particular dietary products are required for the treatment of certain chronically ill and handicapped children. Because of the costs of some of these dietary products and the important counseling associated with use of such products, families may require financial assistance—yet many insurance plans still make no provision for such products or services.

These reimbursement problems persist, despite the fact that the Congress, numerous task forces, professional organizations, and agencies have recognized the need and value of providing nutrition services as a part of ambulatory health care services and acknowledged their cost-effectiveness in preventing and treating disease and disability (*32-34*). Nonetheless, there still has not been any nationwide action on the part of public and private health insurers to include nutrition as a reimbursable service. In some instances, such lack of support reflects a simple undervaluing of the benefits and importance of nutrition services, and a consequent reluctance to finance such services. It is also the Panel's view, however, that nutrition services are but one of a broader class of services that third-party payers typically do not support primarily because the precise content of the service is not well defined, because there is lack of clarity about the circumstances under which such services are best provided and paid for, including which mixes of personnel are best suited to provide such services, and related concerns. In chapters 5 and 9, this issue is taken up in detail and a recommendation made to increase the health service research, evaluation, and similar studies needed to analyze such issues for selected services, including nutrition services, with the expectation that such studies will significantly increase the extent to which these services are financed. As a simultaneous process, however, and as a general principle, *the Panel urges that both public and private third-party payers reorient their financing policies to the extent reasonable, given existing information about how best to provide and pay for nutrition services, to reflect more adequately the importance of nutrition services in maternal and child health care.* We urge, for example, that private and public insurance coverage of special dietary products and services be extended.

The Panel is especially concerned that nutrition-related services be adequately included in the major publicly financed maternal and child health programs—Title V and EPSDT—and in selected additional programs with broader mandates—Head Start, and the primary care programs supported by the Department of Health and Human Services' (DHHS) Bureau of Community Health Services (BCHS). The discussion of these programs, which follows, is presented within the context of a broader Panel concern that as nutrition services are forced to compete for scarce health dollars, they are often decreased, eliminated, or transferred from one funding source to another. In such an environment, they often lose support and are almost never expanded or provided additional funding.

Title V

As a part of their broad health mandate, the maternal and child health programs authorized by Title V of the Social Security Act established the first concerted and continuous national effort for the development of nutrition services in State health agencies, and later defined the nutritional care model for pregnant women, children and adolescents through the Maternity and Infant Care (MIC) and Children and Youth (C&Y) projects. Nutrition services under Title V, carried out in partnership with State and local health agencies, include screening and assessment of nutritional status, nutrition counseling and education, referral to available food programs and other types of assistance programs in the community, and followup. Significant numbers of mothers and children receive nutrition services through specialized health programs in adolescent health, mental retardation, intensive newborn care and others. In 1978, over 1,200 children with inborn errors of metabolism received care and dietary treatment through 72 specialized centers supported in part by Title V (*35*). With regard to this latter service, the Panel finds such centers especially valuable and *urges that additional funds be provided via Title V and other appropriate programs to strengthen regional clinical centers that provide clinical backup to consulting primary care physicians and* *highly specialized dietary products to those patients for whom they are prescribed.*

Because Title V is a formula grant program offering substantial autonomy to the States, specific nutrition services are not mandated in the legislation but are included in the regulations as one of several eligible "medical services." In order to ensure that administrators allocating Title V resources continue to assign appropriate priority to the support of nutrition services, *the Panel recommends that Title V regulations continue to define nutrition services as one of several eligible medical services, and thereby maintain the position of nutrition services in the broad array of maternal and child health activities financed by this program. Similarly, Federal Title V leaders should indicate clearly to the States that, given the importance of nutrition for maternal and child health, nutrition services should be sustained and strengthened despite current budgetary pressures.*

The Panel also notes that the current National Public Health Reporting System used for Title V does not inventory the number and location of programs that have a nutrition component, the number of nutritionists being supported with Title V funds, nor the number of mothers and children who are receiving nutrition services. Rather, nutrition is combined under "other services" to simplify reporting. The result, however, is to obscure both the nature and extent of Title V nutrition services. To overcome this problem, *we recommend that those responsible for collecting data on Title V expenditures collect more specific information regarding the recipients and staffing of nutrition services, and, to the extent possible, the impact and cost-effectiveness of such services.* We add, however, that this recommendation for improved reporting of Title V nutrition expenditures and activities is only a small part of a broader need for improved data on the full Title V program generally, as discussed in vol. II of the Panel's report.

EPSDT

EPSDT recently enlarged and improved its nutrition assessment component to ensure that the nutritional status of eligible children is assessed and that appropriate referral and treatment services are provided. Specifically, the State program and penalty regulation issued in May 1979 requires that States ensure that the nutritional status of children participating in the EPSDT program be assessed; and guidelines issued in May 1980 recommended that nutritional assessment be a routine part of the overall assessment of a child's health. This process is to include: basic questions about dietary practices to identify unusual eating habits or diets which are deficient or excessive in one or more nutrients; complete physical examination including dental examination; accurate measurement of height and weight; and various laboratory tests to screen for iron deficiency, lead toxicity and, in some instances, serum cholesterol. If such information does not suggest nutritional problems, then the child is not referred for further nutritional assessment at that time, but is to receive nutrition education to promote health and prevent nutritional disorders. If there is suggestive evidence of dietary inadequacy or nutritional problems, then further assessment is to be done, and the EPSDT program is to arrange for preventive, treatment, and followup services including dietary counseling and nutrition education based on the needs of the child and family, through direct provision of services or appropriate referral.

The Panel supports the increased specificity regarding nutrition services in these EPSDT guidelines. To ensure that the States comply with such directives and that EPSDT is closely linked to other community nutrition resources, *the Panel recommends that the Health Care Financing Administration monitor on a yearly basis the States' implementation of the nutritional assessment guidelines for EPSDT programs. State Title XIX agencies should reimburse treatment services including appropriate laboratory procedures, counseling, and medications related to nutrition. In addition, States should develop cooperative arrangements with the WIC and other food and nutrition programs in order to enable them to easily refer children at nutritional risk to such programs.*

Head Start

Head Start provides 3–5 year old children from low-income families with comprehensive education, social, health and nutrition services. Provision is made for parent involvement in program planning and operation and for education of parents regarding child development, health and nutrition. In 1979, about 425,000 children and their families were being served by 1,200 grantees operating over 10,000 centers. About $70 million was spent on food, $53 million of which was reimbursed by the U.S. Department of Agriculture (USDA) Child Care Food program. About 12.8 percent of Head Start funds are spent on the program's nutrition component (*36*). Not only is the provision of meals and snacks required in Head Start projects, but so also is nutrition assessment and education for children and their parents. Nutrition services are designed to complement other program components, i.e., health and education. As noted in other sections of this report, the Panel strongly supports the Head Start program generally and would urge that it play a greater leadership role in strengthening child nutrition. Specifically, many low-income children participate in child day care programs that do not meet Head Start standards, including those related to nutrition. The Panel recommends that State and local authorities undertake efforts to *extend the Head Start nutrition model through linkages with other community health and social services programs and through use of existing Head Start programs as training sites to enhance the nutrition related skills of staff from other child day care centers.*

Primary Care–Community Health Programs

BCHS supports the concept of nutrition services as an integral component of all primary health care programs. In 1979, over 3.7 million people were served in Community Health Centers. Estimates are that 80 percent of those served were children and women of childbearing age (*37*). The legislation, regulations and funding criteria for Community Health Centers (including migrant health centers, Appalachian Health Demonstration programs, Rural Health Initiative and Urban Health Initiative projects) include nutritional assessment and referral as a preventive health service and define supplemental health services to include nutrition education. The same core of nutrition services included in administrative guidance for Title V applies to these programs. However, development and expansion of nutrition services in Community Health Centers are hampered by the same fiscal constraints noted under Title V. Identifying resources for support of nutrition services in these programs remains problematic.

The Panel supports recent efforts to inform all grantees about available Federal and nonfederal resources to improve the nutritional status of individuals in these programs and the requirement that all BCHS ambulatory health care projects make necessary links to the WIC program. We also find that more needs to be done to foster coordination and cooperation between State and local public health nutrition services and nutrition services in Community Health Centers.

Strengthening Public Food Programs

A third strategy for improving the nutritional status of mothers and children is to strengthen existing public food programs which typically focus on high-risk groups such as the poor. The major publicly financed food programs in the U.S. provide direct intervention through food subsidies or supplements. They include the Food Stamp program; the Supplemental Food Program for Women, Infants and Children (WIC), which also includes an educational component; school feeding programs; child care and summer feeding programs; and the special milk program.

Earlier in this chapter we asserted that widespread starvation and malnutrition are no longer the problems they once were in the United States. That view notwithstanding, it would be incorrect to conclude that the problems of hunger and basic nutritional deficiencies have been either totally or permanently solved. In fact, undernutrition still causes poor growth and development and deficiency disorders among some poor and minority women and children, especially those living in rural and impoverished inner city areas without adequate access to health and nutrition services. As the ratio of poor children to affluent ones continues to rise, and as income support declines in real value during a period of inflation, unemployment, and fiscal austerity, gains made in recent years could disappear. Along with the very poor, several other groups merit special attention and vigilance: migrant families, non-English speaking families, refugees, Native Americans, and residents of American trust territories. The threat of resurgent hunger among children of the poor is serious enough to require extensive nutritional surveillance as a high priority of national nutrition policy and despite the gains achieved in recent years, further efforts are warranted to eliminate hunger altogether and to reduce iron deficiency and other serious nutritional problems among low-income and at-risk populations of children and pregnant women. Adequate, nutritious food for all remains the greatest single policy objective. In addition, the various food supplement programs must face the newer challenge of responding to emerging nutritional concerns about the role of diet in health promotion and the prevention of chronic degenerative diseases.

Although data indicate that Federal programs have been effective in alleviating hunger and malnutrition, several issues must be addressed if they are to be effective in preventing the dietary imbalances now dominating nutrition concerns. Of primary importance are the extent of participation, the level of benefits, and coordination across programs. Participation rates in most nutrition intervention programs have historically been low. For example, it is estimated that less than 25 percent of the eligible population is participating in the WIC program and that the School Breakfast program is available to only 30–35 percent of school-age children (*36*). To make these programs more effective, the key reasons for nonparticipation need to be identified. Such information can be used by policymakers as the basis for designing appropriate actions to increase program participation. A second issue is the level of benefits in each program necessary to promote good nutrition. This involves not only how much food needs to be included in a meal or food package, for example, but also the more difficult task of determining the type and quality of nutrition education needed to effect behavioral change. In the sections below, suggestions are made for improving the major public food programs.

Special Supplemental Food Program for Women, Infants, and Children (WIC)

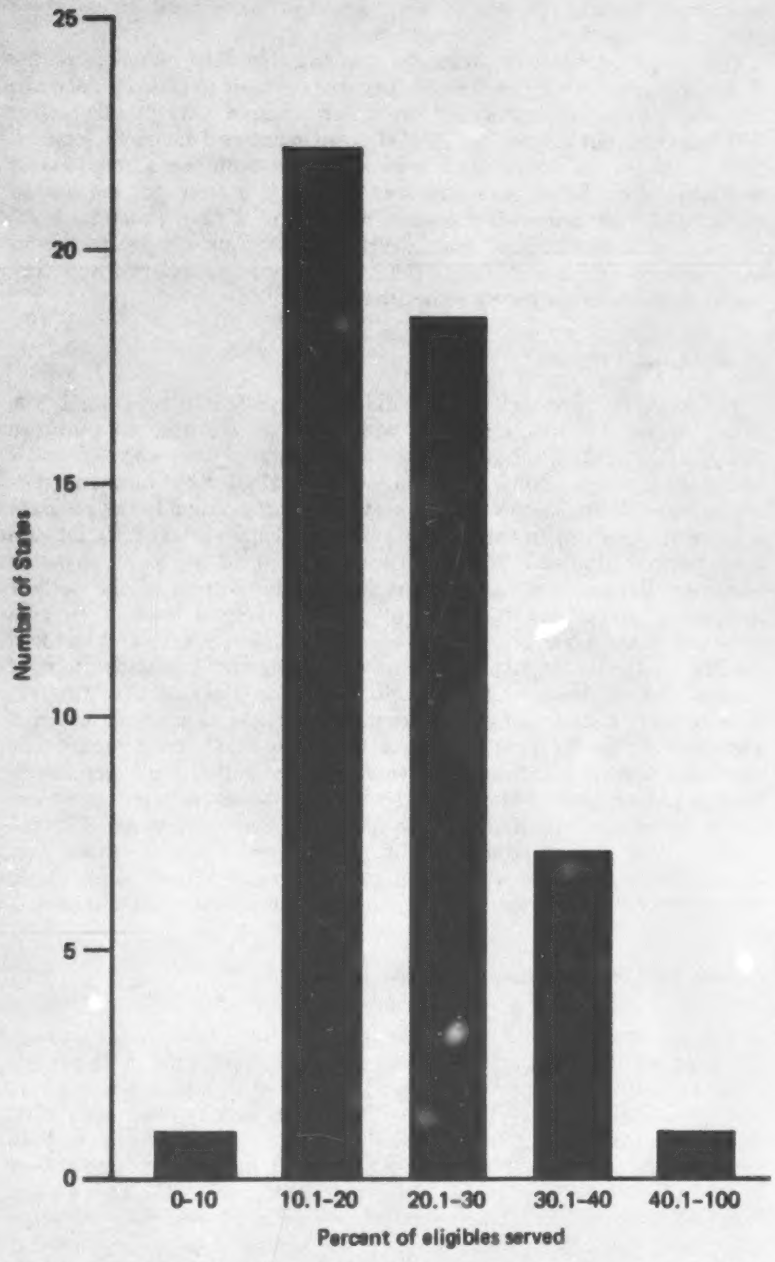
The WIC program provides supplemental, nutritious food to low-income pregnant and lactating women and infants and children up to age 5 who, because of poor health, inadequate nutrition, or both, are at nutritional risk. Created by Congress in 1972 as a pilot program with an annual budget of $20 million, WIC has grown to a program financed in 1980 at about $750 million annually and reaching approximately 1.8 million women, infants, and children under 5. Although WIC has expanded rapidly since its inception, current participants are but a small fraction of the 9.1 million people estimated to be eligible by income criteria alone to participate in the program (*38*). Many of these eligibles who are also nutritionally in need of WIC benefits cannot participate because of inadequate funding. At present, there are approximately 50,000 known eligible persons on the waiting list who are in need of service but live in areas served by agencies that have already reached their quota.

The WIC program is unique among Federal food programs in that, while administered at the Federal level by USDA, it is administered at the State and the local levels as an adjunct to the health care delivery system. Local agencies operating WIC programs are required to see that health services are available to WIC participants. The linkage of WIC to prenatal and child health care services is one of the best aspects of the program, but has proven to be one of the most difficult to implement. Some local WIC programs have expanded in size and scope so rapidly that they have exceeded the capacity of existing maternal and child health services. In addition, there remain areas in this country without adequate health services; needy persons in these areas are categorically ineligible for WIC services because no local agency can guarantee the required availability of health services. Consequently, one option for expanding WIC services is to make maternal and child health services more widely available through increased funding for these health services.

Because of WIC's limited funding, determining who is to be served is very difficult. Typically, certifying physicians, nurses, nutritionists, or other health care professionals must choose among several hundred pregnant women on the waiting list, or must decide whether to drop infants who were recently anemic to make room for new participants. Another problem is that women often enter the program relatively late in pregnancy and average length of participation is only about four months. Better outreach and coordination of the WIC programs with the health care system, and better education regarding the importance of a high quality diet early in pregnancy could help to change this pattern of late enrollment. Increased funding of the program would also help because present limited resources require that eligible women and children in greatest need be served first, and preventive efforts among women early in pregnancy often are curtailed as a result.

A combination of factors makes the WIC program a very attractive policy commitment to enlarge and build upon for the future. The program works, is widely accepted, and is targeted to a needy group where intervention can have a high payoff in both humanitarian and cost-effectiveness terms. Critical food assistance services in pregnancy, birth, and early infancy deserve high priority as a policy focus. *The Panel recommends that over the long run the WIC program be enlarged to serve all women, infants and children who are eligible by income level and nutritional risk. We also urge that maternal and child health programs be expanded and given incentives to collaborate closely with WIC to improve the outcome of high-risk pregnancies especially and ensure good nutrition and health in the earliest months and years of life.*

The Nation is in a period when major additional expenditure for social programs is unlikely, and when the principal concern of policymakers is with improving the efficiency and effectiveness of programs so that limited dollars can accomplish as much as possible. Stronger coordination of effort between WIC and health care programs funded through Title V, and Medicaid/EPSDT targeted on pregnant women and on the care of infants and toddlers at risk offers a high potential for reductions of infant mortality and birth defects, improved health status, and long-term health care cost savings. To help achieve such coordination, *the Panel recommends that State and local health care systems which provide the base for the WIC program should be strengthened by channeling additional dollars through the maternal and child health programs supported through Title V and through Medicaid/EPSDT to enable a strong joint effort combining nutrition and health services directed at pregnant women, infants, and young children at risk of poor health and nutrition.* In the meantime, WIC should continue to act as a magnet to draw health services into areas where food supplements can be provided but no health services presently exist. Examples of the innovative extension of health



Number of States serving specified percentages of financially eligible children and women under the WIC program: United States, 1980

Note: Wyoming and the District of Columbia did not participate in the WIC program as of January 1980.

services in response to WIC can be found in many rural areas. These efforts should be further encouraged and strengthened.

One major problem at present is that the eligibility standards of the WIC program and many of the health care programs to which individuals are referred are not uniform. A child, for example, may be eligible for WIC services but not for an EPSDT assessment and followup services. Such incongruities create serious problems for both the administrators and users of public programs. In the long run, it is clear that the Nation should and must move toward uniform, realistic eligibility standards for all publicly supported food and health care programs. First steps should work toward uniform eligibility for pregnant women, infants, and very young children at nutritional or health risk.

Food Stamp Program

For many low-income households, the Food Stamp program is the major means by which families with children are able to purchase adequate diets. Studies have shown that food stamp users purchase more nutritious foods per dollar spent on food than eligible but nonparticipating households and survey data indicate that participation in the program is associated with significant improvements in dietary intake (*39*). Despite these positive results, it is difficult for most individuals to purchase an adequate diet on food stamps alone, given the erosion of the dollar's purchasing power due to inflation and the minimal level of benefits provided in the Food Stamp program. Low-income women and children usually need to participate in other nutrition programs in addition to food stamps to meet more of their nutritional needs. Because this program remains one of the major public programs that acts to promote maternal and child health, *the Panel recommends that the Food Stamp program be expanded both in numbers of individuals served and in the benefit levels for program recipients.* The program's benefits should be based on a more nutritionally adequate and realistic food plan than now in use. Current efforts in Congress to reduce benefits through a more restrictive food plan should be strongly opposed, and program expansion should be paralleled by vigorous efforts to ensure that abuses of the program are minimized.

School Lunch and School Breakfast Programs

The largest of the child feeding programs are those based in the schools. The National School Lunch program is currently available in 75 percent of all schools and to approximately 90 percent of all school-age children. The program indirectly began in 1935 when commodities were first donated to schools. It officially became a school lunch program in 1946 with the passage of the National School Lunch Act of 1946. The School Breakfast program is a much more recent addition to the set of child nutrition programs. Breakfasts were introduced in a 2-year pilot project in 1967, then made permanent in 1975 and extended to all schools that applied. At present, the program is available to 30 percent of all school-age children, although only 3 million children participate daily in contrast to the National School Lunch program, which provides lunches for approximately 25 million children each school day.

The Panel strongly supports these school feeding programs. We call specific attention, however, to the relatively limited implementation of the School Breakfast program, which is aimed at providing food at precisely the time of day when children need it most. Many children come to school without breakfast or with an inadequate breakfast. In a 24-hour recall of food intake, over 5 percent of children and 10–25 percent of all teenagers reported having had no breakfast (*9*). Such information is especially distressing given the current view that the most productive school learning takes place during morning hours and that hunger during this period can seriously impede concentration and classroom participation by youngsters (*40*). Despite the potential value of the School Breakfast program in addressing this issue, it is apparent that many children do not benefit from it. By 1979, almost all States had the breakfast program, but only 19 had breakfast programs available in at least one-fourth of their schools that have the lunch programs. Despite Federal monetary incentives, net program availability has increased by only 15,000 schools since the program was made permanent in 1975 (*36*).

The reasons for this slow implementation involve numerous State and local administrative problems and some local opposition. Administrative issues pertain to problems in the simultaneous scheduling of breakfast and busing, lack of storage and preparation facilities for two meals per day, and the financial stress of operating two meal programs. In some communities there is disagreement over the level of school responsibility in providing food to children and the extent to which family breakfasts will decline if breakfasts are offered at school. Similarly, many school authorities believe that morning feeding of children should be the role of the family, not the school. These are not problems inherent in the program, but rather are issues of local priority and value orientation.

Despite such concerns, the Panel finds a great need for the program and therefore *recommends that the major school feeding programs receive continued support, and that State leaders especially encourage greater local participation in the School Breakfast program. Schools in the low-income areas should continue to receive priority for beginning new programs.* It is in these schools that the greatest need for supplements to the food received at home is evident.

Since many schools that provide a lunch program do not offer a breakfast program, different incentives may be necessary. Financial incentives, such as providing reimbursement for some nonfood costs, already exist and should be further emphasized. Consulting services could also be provided to help systems modify school schedules to coordinate them better with breakfast schedules. At the local level, information on the benefits of a breakfast program and the number of children who would benefit could be used to generate community support. Because so few schools now participate, expansion of the School Breakfast program may be one of the most cost-effective means to increase the amount of nutritious food available to school-age children.

Other Public Programs

Two other public programs with special relevance should be noted: the Commodity Supplemental Food Program (CSFP) and Aid to Families with Dependent Children (AFDC).

CSFP distributes food directly rather than providing vouchers to be redeemed in the grocery store, which is the emphasis of WIC. It tends to be oriented to income eligibility rather than to eligibility based on nutritional risk. There have been no evaluations of CSFP comparable to those performed on WIC, although one is scheduled for FY 1981. There are some major differences in the design of the two programs—notably the absence of a strong health care component in the commodity program—which may produce different effects. As a general matter, *the Panel urges that over time, the Commodity Supplemental Food Program become more closely related to the provision of preventive and primary health care services.*

With regard to AFDC, whose cash assistance payments now go to over 7 million of the Nation's children in 3.4 million families, the Panel is aware that some critics have suggested that these payments in themselves are enough to cover food costs for low-income children and their parents. Our findings are different. In 32 States, AFDC payments do not meet the federally determined minimal standard of assistance. Food allowances in 49 States fall below the Federal minimum for a family of two, and in 53 States and territories they fall below the minimum level for a family of four (*41*). At present, four-person families on AFDC receive an average of only $1,620 per year for food. In addition, high inflation is rapidly making food more expensive and State legislatures are not inclined to increase welfare benefits. These data suggest that in most States, public assistance allowances are not sufficient to provide an adequate diet. *There is an urgent need to increase public awareness of the inadequacy of AFDC allowances and to enlist public support and commitment to improve such allowances so that vulnerable children have access to an adequate diet and other basic essentials of life.*

Research

A fourth strategy we suggest focuses on the inadequate national commitment to nutrition-related research. Although basic research on nutritional requirements of children has expanded in the last years, applied nutrition research has not.

Three major types of needed nutrition research that have come to the Panel's attention are:

(1) *Better definition and understanding of children's diet, nutrition and health status.* Currently, we have only fragmentary information regarding the dietary, nutritional and health status of mothers and children. This is partly due to the absence of adequate methodologies for collecting such information, but also to a general inattention to these issues. Some standards and criteria used to evaluate nutritional status are extrapolated from

those designed for adults and may be inappropriate for children. Also we have only preliminary information regarding the impact of intervention programs on the nutritional and dietary status of this population, due in part to inadequate evaluation methods and inadequate funding for such studies.

(2) *Identification of individual and family behaviors that increase children's risks of disease, and development of effective strategies for helping families to change nutrition-related practices that adversely affect children's health status.* Diet and health behavior are learned in social settings. It should be possible to identify families in which food practices and orientations are in need of improvement. Imaginative strategies must be designed to help families gain the knowledge and motivation to alter their practices. Further, we need a greater understanding of the dynamics of eating pattern development in childhood, including research on the relationship of various family structures and styles on the food choices of children. Until we understand how behaviors develop and what influences them, our nutrition education efforts with children are little better than scattershots. The effects of advertisements, especially those on TV, on dietary habits are particularly important to assess. Finally, we must begin to examine systematically trends in dietary intake in order to understand the possible policies and programs which can offset adverse trends and enhance positive ones.

(3) *Greater understanding and documentation of the effects of early feeding patterns and nutritional status on long term development and adult health status.* Although the significance of good nutrition to lifelong health is increasingly appreciated, more data are needed regarding the effects of specific nutrient intakes (e.g., cholesterol, salt) on later health. For example, we require more information on the existence of "critical periods" in development with nutritional significance, and the length of time certain substances can be ingested beyond which particularly adverse effects cannot be reversed. Prospective, longitudinal studies to develop such a data base are likely to be prohibitively expensive. However, innovative, creative analysis of cross-sectional and already available limited longitudinal data (e.g., persons evaluated in both HANES I and II studies) may provide some of the desired data and suggest appropriate designs for future studies.

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SECTION III

THE CONTENT, ORGANIZATION, AND FINANCING OF HEALTH SERVICES

CHAPTER 5

NEEDED SERVICES

In creating this Panel, the Congress asked for recommendations regarding "... the appropriate type and quantity of preventive health care and other health services needed by children in general and by particular types of children at risk." We discovered early in our work that one overriding question would have to be answered before we could fulfill this mandate or address other issues and problems about which Congress sought advice: What personal health services should be available to mothers and children?

The Panel firmly believed that its work should be based on an understanding of the health care mothers and children actually need, rather than on such factors as apparent demand for services. It became clear that until we could define the range of services that should be available, it would be difficult to determine how best to organize and finance health services for mothers and children, to assess provider arrangements, review personnel requirements, or to examine any other major aspect of maternal and child health care. Furthermore, we felt a clear definition of needed services would be useful to groups such as businesses and unions who must decide what type of coverage to seek in group insurance plans, to third-party payers who must determine what services to cover in their policies, and to child health advocates seeking to assess the adequacy of services currently available to their constituencies and to press for needed improvements. For all these reasons, the task of defining needed services became a fundamental first step in the Panel's work and served as the cornerstone for much that follows in subsequent chapters.

UNDERLYING ASSUMPTIONS

In developing actual lists of needed services, the Panel was guided by several underlying assumptions. First, we took a broad view in defining the types of procedures, care, and actions that should comprise health services for mothers and children. As described in chapter 1, the health problems pertinent to mothers and children range from the biomedical to the psychosocial, not only in their causation, but also in their treatment

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and prevention. It is the Panel's view, therefore, that the health services needed by this population will necessarily entail not only traditional medical care, but also a range of services such as counseling, anticipatory guidance, and various information and education activities that are oriented to psychosocial issues. Furthermore, if an individual cannot physically get to a source of needed care, or cannot communicate with a health professional once there, the health service is available in theory only. Thus, the services that should be available include selected transportation, outreach, translator and related services. In recognition, however, that such activities are not personal health services in the strict sense, they are referred to in this report as "access-related services."

Second, the Panel directed its attention primarily to services that are preventive in nature and are typically delivered through primary care systems. We have itemized the elements of preventive care in greater detail than the elements of therapeutic and rehabilitative services, although all three are obviously components of needed care and appear in the lists of services. This orientation stems from the Panel's mandate, which emphasizes disease prevention and health promotion in mothers and children as distinguished from treatment needs, and from the Panel's belief that many of the strategies most likely to decrease overall mortality and morbidity in this group lie in the domain of preventive services and primary care.

The Panel fully appreciates the vital importance of secondary, tertiary and rehabilitative services. This Nation is a world leader in the medical services that can be mustered to help a child seriously ill with an infectious disease, suffering from severe burns, or injured badly in an automobile accident, to cite but a few examples. Our ability to care for an ill newborn is virtually unmatched, and our technological interventions to help the physically handicapped constantly increase in sophistication. Clearly, secondary, tertiary, and rehabilitative care are essential components of health services, and nowhere is this more true than for children with handicapping conditions and chronic illness. Systems for meeting such special needs are discussed elsewhere in this report, particularly in chapter 8.

A third issue considered by the Panel in defining needed services was that of efficacy. The Panel would like to list as "needed" only those services whose efficacy has been thoroughly documented experimentally and validated through experience, but the practice of medicine and the content of health care generally is often as much art as science. Many health care interventions, both preventive and therapeutic, have achieved their place in the armamentarium of health services primarily by thoughtful practice and consensus. In our view, the absence of complete efficacy data should not preclude efforts to define the health services that should be available to mothers and children. Reasoned judgment, prudence, and experience, supplemented by available data where possible are viewed by the Panel as adequate and legitimate guides in the task. Public policy can seldom wait for perfect information before proceeding; sometimes decisions must be based on expert opinion and informed judgments. In the long run, research conducted through the efforts of a number of groups currently at work or proposed by the Panel can increase the extent to which health services are science based.

Another issue confronted by the Panel was the question of the cost-effectiveness of the various services on our lists. In general, the Panel did not seek to determine the cost-effectiveness of particular services, because we believe that cost-benefit and cost-effectiveness analyses seldom provide policymakers with definitive answers about the value and proper role of a given service. Decisions can be informed and assisted by the findings of such analyses, but they often rest ultimately on value judgments (*1*). Assessing the cost-benefit of counseling to parents of chronically ill children, for example, will always hinge to some degree on the value assigned to providing comfort and solace. The one exception to this general avoidance by the Panel of cost-effectiveness analysis follows in the discussion of a set of three mininum basic services.

The Panel is keenly aware that a variety of factors such as provider arrangements, reimbursement policies, and eligibility criteria will be decisive in determining the quality and accessibility of the services we have designated as needed, and whether they are truly available to and used appropriately by mothers and children. For example, if an insurance policy excludes a needed service in its benefit package, the chances are decreased that the service will be widely used, even if it is important, as is the case with dental services; if a hospital discharges new mothers and infants without explicitly assuring that they are linked to a source of pediatric care, some will join the group of unserved "hard to reach" people. In the Panel's view, the recognition of the influence of such system variables should undergird any discussion of needed services. Accordingly, much of this report is directed to issues in the organization and financing of health services, and the governance structures that influence the health care system.

LISTS OF NEEDED SERVICES

Included in this section are lists of needed services developed by the Panel and shaped by the views just described. The lists draw heavily on standards issued by various professional societies and similar lists that expert groups have developed in recent years. Principal sources included:

- Standards of practice issued by the American Academy of Pediatrics (AAP) and the American College of Obstetricians and Gynecologists (ACOG) (*2–4*)
- The list of needed services contained in the Report by the Task Force on Pediatric Education, *The Future of Pediatric Education* (*5*)
- The American Public Health Association's publications, *Ambulatory Maternal Health Care and Family Planning Services*, and *Proposed Benefits To Be Covered on a First Dollar Basis Under National Health Insurance* (*6, 7*)

- The Institute of Medicine's background paper, *Preventive Services for the Well Population* (*8*)
- Both volumes of the Surgeon General's report, *Healthy People* (*9*)
- The Canadian Medical Journal Association's report, *The Periodic Health Examination* (*10*)
- The Breslow-Somers proposed "Lifetime Health Monitoring Program" (*11*)
- *Dollars and Doctors Are Not Enough*, published by the Children's Defense Fund (*12*)
- The background papers prepared for the Panel by Aronson, Klerman, and Kessel *et al.* (*13*) (see appendix C)
- Lists of services mandated by Medicaid, including the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program (*14*)
- The health service benefits proposed by the Child Health Assurance Program (CHAP) legislation
- The benefits provided by several private health insurance plans

By combining and building on the perspectives of these various groups, the Panel believes that a strong first step has been taken in defining the health services that should be available to mothers and children. We emphasize, however, that these lists are only a beginning. Because of the continuing flow of new scientific evidence, the changing nature of health problems over time, and valid differences of professional judgment concerning interpretation of existing data, these lists should be subject to periodic reexamination and modification by appropriate groups that we propose at the end of this chapter, such as the Board on Health Services Standards.

In reading the lists, several important caveats and explanatory notes should be kept in mind: First, the lists often describe a set of services preceded by the phrases "such as," "as needed," or "as appropriate." These phrases are designed to convey the notion that services must be tailored to an individual and take into account age, stage of development, past history, present risk, and so forth. The lists are not a practice manual, but rather a compendium of broad categories of services that should be available and used to varying degrees and in varying combinations by an individual. Second, the lists also use the phrase ". . . to include." This phrase is intended to suggest that the units that follow are minimum components of a broad category, rather than examples or possible items for inclusion. For example, the topics to be covered in prenatal counseling—which in the list are preceded by the phrase "to include"—are viewed by the Panel as essentially a minimum set. Third, the lists intentionally avoid notations of periodicity—such as the desired frequency of health examinations or specific immunization schedules. In general, the Panel believes that the practice standards developed by such groups as the AAP and ACOG are most adequate at present for those services for which they have recommended specific schedules. Fourth, the age and developmental boundaries of the lists were somewhat arbitrarily determined. Although they correspond to the boundaries of many other lists of services reviewed, we recognize the inherent artificiality of such compartmentalization.

Health Services for Women of Reproductive Age, With a Special Focus on Services Relevant to Reproduction

I. Services for nonpregnant women that relate to the occurrence and course of future pregnancy
  A. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic, that can adversely affect future pregnancy, fetal development, and maternal health such as:
    1. Sexually transmitted diseases
    2. Immune status (such as rubella)
    3. Gynecological anatomic and functional disorders
    4. Organic medical problems such as renal and heart diseases, hypertension, diabetes, and endocrine problems
    5. Inadequate nutritional status, including both under- and overweight
    6. Problems relating to fertility
    7. Genetic risk (see I D)
    8. Significant dental problems such as periodontal disease
    9. Occupational exposures
  B. Diagnosis and treatment[b] or referral and followup of mental health and behavioral problems, both acute and chronic, that can adversely affect pregnancy, fetal development, and maternal health such as:
    1. Alcohol abuse, drug addiction or abuse, other substance abuse, and cigarette smoking
    2. Significant mental disorders such as schizophrenia and depression
  C. Comprehensive family planning services, including:
    1. Information, education, and counseling regarding family planning concepts and techniques, and other issues such as the importance of prenatal care, and risks to mother and child of childbearing at extremes of the reproductive age span
    2. Physical examination, including breast and pelvic examination, as indicated, and tests such as a Papanicolau smear, G.C. culture, urinalysis, and serological examination as appropriate

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[a] Services for both acute and chronic medical conditions include inpatient and outpatient services, clinic and physician office services, emergency services, laboratory and X-ray services, provision of prescribed drugs and vaccines, medical supplies, and rehabilitation services.

[b] Services for both acute and chronic mental health conditions include inpatient and outpatient hospital services, long-term psychiatric care, clinic and physician office services, counseling and anticipatory guidance, crisis intervention services, laboratory services, and provision of prescribed drugs.

[c] Nutrition services include screening-assessment of nutritional status; dietary counseling to assist people to meet their normal and therapeutic nutritional needs; nutrition education; and provision of, or referral to, resources needed to improve or maintain nutritional health, that is, supplemental food assistance, special feeding equipment, and food service programs.

[d] Home health services include the provision of medical, nursing, dietary, and rehabilitative services in the home; homemaker services including assistance for the family in routine household responsibilities when illness or disability interferes with such functions.

   3. Provision of family planning methods and instruction regarding their use
   4. Pregnancy testing with attendant counseling and referrals as appropriate (including prenatal services, adoption, and abortion)
   5. Infertility services, including counseling, information, education, and treatment
   6. Sterilization services, including counseling, information, education, and treatment
 D. Genetic screening and related services as needed to detect persons at risk, with counseling and referral as appropriate
 E. Home health and homemaker services[d]

II. Services in the prenatal period
 A. Early diagnosis of pregnancy
 B. Counseling regarding plans for pregnancy continuation
   1. For those electing to carry to term, referral for and provision of prenatal care and of adoption services if indicated; referral to childbirth preparation classes as desired
   2. For those electing abortion, referral to and provision of first or second trimester abortion, including family planning counseling
 C. Prenatal care services including:
   1. History (general medical, social and occupational, family and genetic background, health habits, previous pregnancies, and current pregnancy)
   2. General physical examination including blood pressure, height and weight, and fetal development
   3. Laboratory tests as appropriate, such as VDRL, Papanicolau smear, G. C. culture, hemoglobin-hematocrit, urinalysis for sugar and protein, Rh determination and irregular antibody screening, blood group determination, and rubella test
   4. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic, preexisting or arising during the prenatal period, that can adversely affect pregnancy, fetal development, or maternal health
   5. Diagnosis and treatment[b] or referral and followup of mental health problems, both acute and chronic, preexisting or arising during the prenatal period, that can adversely affect pregnancy, fetal development, or maternal health
   6. Nutritional assessment and services[c] as needed. Provision of vitamin, iron, and other supplements as appropriate
   7. Dental services with special attention to detection and treatment of periodontal disease
   8. Screening, diagnosis (including amniocentesis), and counseling with followup for selected fetal genetic defects (such as neural tube defects, Down's syndrome, Tay-Sach's disease and sickle cell disease) with abortion services available
   9. Services to identify and manage high-risk pregnancies to

include provision of appropriate prenatal and perinatal care services for labor, delivery, and newborn care

10. Counseling and anticipatory guidance with followup and referrals as needed regarding:
    a. Physical activity and exercise
    b. Nutrition during pregnancy, including the importance of adequate but not excessive weight gain
    c. Avoidance during pregnancy of smoking, alcohol, and other drugs; and of environmental hazards including radiation, hazardous chemicals, and various workplace hazards
    d. Signs of abnormal pregnancy and of the onset of labor
    e. Preparation of the woman (and her partner where appropriate) for labor and delivery, including plans for place of delivery and feelings about use of anesthesia
    f. Use of medications during pregnancy
    g. Infant nutritional needs and feeding practices, including breast-feeding
    h. Child care arrangements
    i. Parenting skills, including meeting the physical, emotional, and intellectual needs of the infant, with specific appraisal to detect parents at risk of child abuse or neglect
    j. Planning for continuous and comprehensive pediatric care following delivery, including arrangements for a pediatric antenatal visit to link the family to pediatric care
    k. Emotional and social changes occasioned by the birth of a child, including changes in marital and family relationships, the special needs of the mother in the postpartum period, and preparing the home for the arrival of the newborn
    l. Other relevant topics in response to patient concern

D. Home health and homemaker services[d]

III. Services in the perinatal and postpartum periods
  A. Assessing the progress of labor and the condition of the mother and fetus throughout labor
  B. Medical services during labor and delivery for diagnosis and management of conditions threatening the mother and/or infant, including the availability of a Caesarean section when indicated
  C. Delivery of the baby by a qualified professional in a facility that has services needed to manage medical emergencies of the mother and/or newborn, or has ready access to such services
  D. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic, preexisting or arising during the perinatal and postpartum periods that can adversely affect the mother's child-caring abilities
  E. Diagnosis and treatment[b] or referral and followup of mental health or behavioral problems, both acute and chronic, preexisting

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or arising during the perinatal and postpartum periods (including maternal depression) that can adversely affect the mother's child-caring abilities

F. Counseling and anticipatory guidance with referrals and followup as needed regarding:
   1. Infant development and behavior
   2. Infant nutritional needs and feeding practices, including breast-feeding.
   3. Automobile restraints for infants and children, and general accident prevention concepts (especially home accidents and accidental poisoning)
   4. Infant stimulation and parenting skills, with specific appraisal to identify parents at risk of child abuse or neglect
   5. Need for and importance of immunizations
   6. Effect on children of parental smoking, use of alcohol and other drugs, and other health-damaging behaviors
   7. The importance of a source of continuous and comprehensive care for both mother and child, including identification of available resources to help with such problems as illness in the newborn or breast-feeding difficulties
   8. Recognition and management of illness in the newborn
   9. Hygiene and first aid
   10. Child care arrangements
   11. Other relevant topics in response to parental concern

G. Home health and homemaker services[d]

H. Routine postpartum examination, with referrals and followup as needed, including:
   1. Laboratory services as appropriate
   2. Family planning services
   3. Counseling as appropriate regarding the topics noted in III F above and other relevant topics in response to parental concern

IV. Health education regarding such topics as:
   A. Items in II(C)10 and III F above
   B. Developing positive health habits
   C. Using health services appropriately
   D. Using community health resources such as the Supplemental Food Program for Women, Infants and Children (WIC), food stamps, welfare and social services that bear significantly on health status

V. Access-related services:
   A. Transportation services as appropriate including
      1. Emergency medical transport services for both mother and newborn
      2. Transportation services associated with a regionalized perinatal and/or tertiary care network
      3. Transportation services that facilitate obtaining needed health services

B. Outreach services
C. Hotline, translator, and 24-hour emergency telephone services
D. Child care services to facilitate obtaining needed health services

Health Services for Infants in the First Year of Life

I. Services in the neonatal period
   A. Evaluation of the newborn infant immediately after delivery and institution of appropriate support procedures such as nasal-oral suctioning
   B. Complete physical examination, including length, weight, and head circumference
   C. Laboratory tests to screen for genetically-determined diseases including PKU, hypothyroidism, and galactosemia
   D. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic
   E. Preventive procedures to include
      1. Gonococcal eye infection prophylaxis
      2. Administration of vitamin K
   F. Services of a newborn intensive care unit as appropriate
   G. Nutritional assessment and services[c] and supplementation as needed
   H. Bonding and attachment support activities including provision for extended contact between parents and their infant immediately after delivery and, where desired by the parents, rooming-in arrangements or the equivalent
   I. Arrangements for continuous, comprehensive pediatric care for the newborn following discharge from the hospital
   J. Home health services[d]

II. Services during balance of first year of life
   A. Periodic health assessment to include:
      1. History and systems review (general medical and social, family, and genetic background, with items of inquiry determined by age, developmental stage, and likelihood of potential problems)
      2. Complete physical examination to include:
         a. Height and weight
         b. Head circumference
         c. Developmental-behavioral assessment
         d. Vision and hearing evaluation
      3. Screening and laboratory tests as indicated, including hemoglobin-hematocrit and tuberculin skin test; and, for infants at risk, such procedures as lead poisoning, parasite, and sickle cell screening
      4. Nutritional assessment and services[c] and supplementation as needed (including provision of such supplements as iron and vitamin D, and fluoride if community water supply is not fluoridated)

B. Immunizations according to nationally recognized standards
C. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic
D. Home health services[d]

III. Services for families during infants' first year of life
A. Counseling and anticipatory guidance with referrals and followup as needed regarding:
   1. Infant development and behavior
   2. Maternal nutritional needs, especially if breast-feeding, and infant nutritional needs and feeding practices
   3. Automobile restraints for infants, and general accident prevention concepts (especially home accidents and accidental poisoning)
   4. Infant stimulation and parenting skills, with specific appraisal to identify parents at risk of child abuse or neglect
   5. Need for and importance of immunizations
   6. Effect on children of parental smoking, use of alcohol and other drugs, and other health-damaging behaviors
   7. The importance of a source of continuous and comprehensive care for mother and child, including identification of available resources to help with such problems as sudden illness or breast-feeding difficulties
   8. Recognition and management of illness
   9. Hygiene and first aid
   10. Child care arrangements
   11. Other relevant topics in response to parental concern

B. Counseling and provision of appropriate treatment[a,b] and/or referral to appropriate services (including home health and homemaker services[d]) as needed for parents:
   1. Who have chronic illnesses, handicapping conditions, alcohol or drug problems, mental health problems (including maternal depression), or other health problems that seriously affect their capacity to care for the infant
   2. Whose infant is seriously ill
   3. Whose infant has a chronic illness or handicapping condition
   4. Whose infant is or is about to be hospitalized

IV. Health education regarding such topics as:
A. Items in III A above
B. Developing positive health habits
C. Using health services appropriately
D. Using community health resources such as WIC, food stamps, welfare and social services that bear significantly on health status

V. Access-related services
A. Transportation services as appropriate including:
   1. Emergency medical transport services for both infant and mother
   2. Transportation services associated with a regionalized perinatal and/or tertiary care network

3. Transportation services that facilitate obtaining needed health services

B. Outreach services

C. Hotline, translator, and 24-hour emergency telephone services

D. Child care services to facilitate obtaining needed health services

Health Services for Children (From 1 Year to Early Adolescence)

This list combines services for children from age 1 to early adolescence. Obviously, some of the items apply primarily to either older or younger children (such as counseling regarding use *by the child* of cigarettes in the former case and initiation of the mumps, measles, and rubella immunization series in the latter).

I. Services for children
  A. Periodic health assessment to include:
    1. History and systems review (general medical and social, family and genetic background, with items of inquiry determined by age, developmental stage, and likelihood of potential problems)
    2. Psychosocial history, including peer and family relationships, and school progress and problems
    3. Complete physical examination to include:
      a. Height and weight, including attention to overweight, underweight, and poor linear growth
      b. Developmental and behavioral assessment
      c. Vision, hearing, and speech evaluation
    4. Screening and laboratory tests as indicated, including hemoglobin-hematocrit and tuberculin skin test; and, for children at risk, such procedures as lead poisoning, parasite, and sexually transmitted disease screening
    5. Nutritional assessment and services[c] and supplementation as needed (including provision of such supplements as iron and vitamin D, and fluoride if community water supply is not fluoridated)
  B. Immunizations according to nationally recognized standards
  C. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic
  D. Diagnosis and treatment[b] or referral and followup of mental health problems, both acute and chronic, including emotional and learning disorders, behavioral disorders, alcohol and drug-related problems, and problems with family and peer group relationships
  E. Counseling and provision of support services as needed to children with chronic illnesses and/or handicapping conditions
  F. Dental services, both preventive and therapeutic, including oral examination, prophylaxis, X-ray, fluoride supplementation if community water supply is not fluoridated, restorations including fillings, orthodontia for significant physical or psychological

impairment, and treatment of dental problems including periodontal disease
G. Home health services[d]

II. Services for children and their families
  A. Counseling and anticipatory guidance with referrals and followup as needed to child and/or parents as appropriate regarding:
    1. Nutritional needs including food purchase and preparation, routine dietary needs, and the importance of a high-quality diet
    2. Automobile restraints for children and general accident prevention concepts (especially home accidents, accidental poisoning, and sports injuries)
    3. Parenting skills, with specific appraisal to identify parents at risk of child abuse or neglect
    4. Need for and importance of immunizations
    5. Medical and child care arrangements for child
    6. Dangers of use by children and effects on children of parental smoking, use of alcohol, and other drugs
    7. Physical activity and exercise
    8. Hygiene and first aid
    9. Dental health
    10. Childhood antecedents of adult illness
    11. Child development (including sexual maturation and adjustment, and developmental and behavioral difficulties)
    12. Environmental hazards
    13. Other relevant topics in response to child and/or parental concern
  B. Counseling and provision of appropriate treatment services[a,b] and/or referral to services (including home health and homemaker services[d]) as needed for parents:
    1. Who have chronic illnesses, handicapping conditions, alcohol or drug problems, mental health conditions (including maternal depression), or other health problems that seriously affect their capacity to care for the child
    2. Whose child is seriously ill
    3. Whose child has a chronic illness or handicapping condition, or a significant behavioral or emotional problem
    4. Whose child is or is about to be hospitalized

III. Health education regarding such topics as:
  A. Items previously mentioned listed in II A
  B. Developing positive health habits
  C. Using health services appropriately
  D. Using community health resources such as WIC, food stamps, welfare and social services that bear significantly on health status

IV. Access-related services
  A. Transportation services as appropriate including:
    1. Emergency medical transport services

    2. Transportation services associated with a regionalized tertiary care network
    3. Transportation services that facilitate obtaining needed health services
  B. Outreach services
  C. Hotline, translator, and 24-hour emergency telephone services
  D. Child care services to facilitate obtaining needed health services

Health Services for Adolescents

I. Services for adolescents
  A. Periodic health assessment to include:
    1. Medical history and systems review (general medical and social, family and genetic background, with items of inquiry determined by age, developmental stage, and likelihood of potential problems)
    2. Psychosocial history, including school progress and problems, out-of-school activities, peer and family relationships, and health-related habits, including sexual activity and use of alcohol and drugs
    3. Complete physical examination including:
      a. Height and weight, with special attention to deviations from normal growth curves
      b. Developmental and behavioral assessment, including sexual development
      c. Vision, hearing, and speech evaluations
    4. Screening and laboratory tests as indicated, including hemoglobin-hematocrit and tuberculin skin test; and, for adolescents at risk, such procedures as lead poisoning, parasite, and sexually transmitted disease screening
    5. Nutritional assessment and services[c] and supplementation as needed
  B. Maintenance of immunizations according to nationally recognized standards
  C. Family planning services with availability of extensive counseling for the adolescent, partner, and family as appropriate; and education on, among other topics, the importance of early prenatal care and risks to both mother and child of childbearing in early adolescence
  D. Diagnosis and treatment[a] or referral and followup of general health problems, both acute and chronic
  E. Diagnosis and treatment[b] or referral and followup of mental health problems, both acute and chronic, including emotional and learning disorders, behavioral disorders, alcohol and drug-related problems, and problems with family and peer group relationships
  F. Counseling and provision of support services as needed to children with chronic illnesses and/or handicapping conditions
  G. Dental services, both preventive and therapeutic, including oral

examination, prophylaxis, X-ray, fluoride supplementation if community water supply is not fluoridated, restorations including fillings, orthodontia for significant physical or psychological impairment, and treatment of dental problems including periodontal disease

H. Home health services[d]

II. Services for adolescents and their families

A. Counseling and anticipatory guidance with followup and referrals as needed for the adolescent and/or parents as appropriate regarding:

1. Nutritional needs, including the importance of a high-quality diet and the risks associated with fad diets
2. Automobile restraints and general accident prevention concepts, including sports injuries
3. Psychosomatic complaints such as those associated with family and school difficulties
4. Dental health
5. Smoking, use of alcohol and other drugs
6. Physical activity, exercise, and sleep
7. Relationship of health-related behaviors in adolescence to adult illness
8. Sexual development and adjustment, male-female relationships, and family life
9. Future plans, including school and vocational plans
10. Other topics in response to adolescent and/or family concern

B. Counseling and provision of appropriate treatment services [a,b] and/or referral to services (including home health and homemaker services[d]) as needed for parents:

1. Who have chronic illnesses, handicapping conditions, alcohol or drug problems, mental health conditions, or other health problems that seriously affect their capacity to care for the adolescent
2. Whose adolescent is seriously ill
3. Whose adolescent has a chronic illness or handicapping condition, or a significant behavioral or emotional problem
4. Whose adolescent is or is about to be hospitalized

III. Services with special relevance for pregnant adolescents choosing to carry a pregnancy to term and keep the baby, and for very young parents

A. Special attention to prenatal services directed at detecting and preventing low-birth-weight infants

B. Indepth counseling regarding

1. Family and partner-spouse relationships
2. Home management and family life with an emphasis on preparation for parenthood
3. Vocational and educational plans

        4. Management of stress associated with caring for babies and young children
        5. Financial planning
    - C. Special educational arrangements as needed to assist the pregnant adolescent and young mother to remain in school and/or obtain needed job skills
    - D. Support services such as infant and child day care, home health and homemaker services,[d] crisis intervention, psychological support services, and services to link the young mother and family to community resources as needed (such as WIC and welfare programs, housing assistance, community mental health centers, vocational counseling and educational agencies, and food stamps)

- IV. Health education regarding such topics as:
    - A. Items in II A above
    - B. Developing positive health habits
    - C. Using health services appropriately
    - D. Using community health resources such as WIC, food stamps, welfare and social services that bear significantly on health status

- V. Access-related services
    - A. Transportation services as appropriate including:
        1. Emergency medical transport services
        2. Transportation services associated with a regionalized tertiary care network
        3. Transportation services that facilitate obtaining needed health services
    - B. Outreach services
    - C. Hotline, translator, and 24-hour emergency telephone services
    - D. Child care to facilitate obtaining needed health services

MAJOR CONCLUSIONS

In developing the needed services lists, the Panel reviewed data regarding the incidence and prevalence of the health problems of infants, children, adolescents, and women of reproductive age; the relative benefits of the interventions available to prevent and treat such problems; the availability and utilization of health services by this population; and, as noted above, similar lists developed by other groups. Such analysis and the process of compiling the lists themselves led us to three major conclusions. First, three broad classes of primary care services—prenatal care, delivery, and postnatal services; comprehensive health care for children through age 5; and family planning services—should become universally available without delay. Second, four additional groups of services are also especially important and are not now adequately available: mental health and related psychosocial services; dental services; genetic services; and access-related services. Third, Congress should establish a Board on Health Services Standards to serve a variety of functions aimed at improving the content, quality, and availability of health services for mothers and children.

Minimum Basic Services

A finding of preeminent importance is the Panel's conclusion that *there are three broad classes of services for which there is such a clear consensus regarding their effectiveness and their importance to good health, that it should no longer be considered acceptable that an individual is denied access to them for any reason, because of financial barriers; barriers resulting from the time, place or manner in which the services are provided; inadequate personnel capacity; or other reasons. These services are:*

(1) *prenatal, delivery, and postnatal care*
(2) *comprehensive health care for children from birth through age 5*
(3) *family planning services*

The Panel has concluded that it is unconscionable for a society such as ours to have any of its members need these services yet not obtain them, particularly because the components of these services are well understood and essentially noncontroversial, their lifelong beneficial impact on health status is indisputable, and they are of virtually equal value and necessity to all segments of the population irrespective of income, geographic location, or other variables.

The Panel also sees a need for the content of and standards of quality for each of these service clusters to be clearly defined. At a minimum, such definition will be needed to implement many of the specific suggestions contained in later chapters, particularly our suggestion that the Federal Government and the States develop new and clear assumptions of responsibility for assuring the availability of these services. *The Panel therefore recommends that, as a first priority, the Public Health Service (PHS) promulgate standards for the content, periodicity, and quality of these three basic clusters of services, for use by the Federal Government, the States, private and public third-party payers, voluntary groups, public programs, private practitioners and all others involved in delivering or monitoring the delivery of these services.* In so doing, the Public Health Service should rely on the appropriate professional societies, the existing health expertise within PHS itself (particularly the Office of Maternal and Child Health and the Maternal and Child Health Administration should it be formed as proposed by the Panel in chapter 11), the National Center for Health Care Technology, the Institute of Medicine–National Academy of Sciences, consumer and advocacy groups, and other bodies as appropriate.

We recognize that the content of each of the three clusters is quite variable in actual practice today, and that in only a few settings does each service include all components itemized in our lists. For example, prenatal care services frequently do not include information, education, and counseling on many of the items enumerated in the lists, despite the

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probability that careful guidance to pregnant women about avoiding such harmful substances as tobacco and alcohol may be one of the most health-promoting components of prenatal care. In the short run, the Panel finds acceptable an approach in which the current, conventional norms governing the content of each of the three services be considered adequate for the purpose of promulgating standards as recommended above. As a long range goal, the Panel urges that all efforts—such as reimbursement policies, curricula for training personnel who will be involved in providing maternal and child health care, and standards of quality as developed by both public and professional groups—be directed to improving and expanding the content of each of the three sets of services in the more comprehensive direction embodied in the lists.

In chapters 6 through 9, a series of recommendations are made for helping to ensure that all individuals have access to these services. These recommendations are based on the Panel's finding that the principal barriers to obtaining the services lie in the way our health system is structured. In some instances, assuring the availability of these services will require removal of financial barriers to obtaining care and new ways of organizing the delivery of care with an orientation to outreach and access-related services, such as revitalized home visiting. In others, what may be needed is a more vigorous commitment to improving and expanding existing systems—as in family planning, which is currently delivered through a pluralistic system adequate for those it reaches but which needs to be expanded to accommodate those still in need. It is also apparent that a major nationwide campaign to help inform and educate individuals on the importance of these services and how to obtain them will be critical. In chapter 3, the influence of the media in conveying such information is noted, and some broad principles of health-related behavior are described. These themes are directly applicable to reaching the goal of assured availability for these three services. Personal actions and choices will always remain a major variable in, for example, whether or not a woman seeks and obtains prenatal care early in pregnancy, even in the best of circumstances. Thus a major campaign to explain the nature and benefits of these services and to motivate individuals to use them will be essential.

In the sections that follow, these three services are discussed in terms of their effectiveness in promoting child health and well-being, and the unmet need for such services. We reiterate our view that for any individual to be in need of these services yet not able to obtain them should be considered unacceptable, and reiterate that reaching unserved groups will probably require system changes directed primarily at increasing access to such services. Selected cost-effectiveness information is also included, although the Panel did not use dollar savings as the screen through which it selected these three clusters of services for priority attention. It happens that these services are highly cost-effective. More important in the Panel's view, however, is their indisputable contribution to health promotion and disease prevention, the value attached to them by individual providers and consumers, and the distressing fact that these services are not fully available to all individuals who need them.

Prenatal, Delivery, and Postnatal Care

The Panel finds services associated with pregnancy, childbirth, and the immediate postpartum period to be essential, but not yet available and accessible to all who need them.

The effectiveness of prenatal care in reducing low birth weight—the most important predictor of illness or death in early infancy and of the need for neonatal intensive care—has been so well demonstrated in various well-controlled studies that even the most skeptical reviewers of the health services literature would agree that this form of preventive care is one of our most valuable in promoting child health. Given no prenatal care, an expectant mother is three times as likely to have a low-birth-weight child. Three-quarters of the risks associated with low birth weight can be evaluated in a first prenatal visit, and interventions can be taken to help reduce such risks. Furthermore, late care or no care is associated with increased prematurity rates, increased stillbirths, and increased newborn mortality. In 1977, neonatal, post-neonatal, and infant death rates were four times higher for patients with no prenatal care than those receiving at least some care. Infants born to women experiencing complications of pregnancy such as toxemia and infections of the uterus have a four to five times higher mortality rate than others. For mothers with such medical conditions as diabetes, hypertension, or kidney and heart disease, there is a higher risk of bearing babies who will not survive their first year. Such risks can be reduced by competent, early medical care (*15*).

Additional data supporting the value of prenatal care were recently cited in the Surgeon General's report, *Healthy People:*

> From 1950 to 1977, infant mortality dropped from 30 to 14 deaths per 1,000 live births. Although some of the improvement was due to greater availability of regionalized intensive care units for newborns, better prenatal services have clearly played an important role.
>
> Maternity and Infant Care (MIC) Projects (which provide prenatal services as a high priority) have consistently been associated with declines in low-birth-weight incidence and infant mortality.
>
> In Birmingham, Alabama, for example, after the MIC project began in 1967, prenatal clinics available for low-income pregnant women increased and the proportion of women receiving prenatal care during the first trimester rose from 24 percent in 1968 to 39 percent in 1978. Although a direct cause-and-effect relationship cannot be determined, infant mortality in this area dropped from 25 deaths per 1,000 live births in 1965 to about 14 in 1977—and infant deaths during the first month of life went from 19 to 10 per 1,000 live births, a 47 percent decrease (*15*).

Interestingly, the precise components of prenatal care that lead to such dramatic differences in reproductive outcome have not been clearly identified. The lower risk undoubtedly is associated with some aspects of medical and obstetrical services, especially for high-risk conditions. It is also highly likely that the counseling of expectant mothers on potential problems for the fetus that may be caused by smoking, alcohol use, and poor nutrition—and referral when necessary to suitable services—is a major contributor to the effectiveness of prenatal care.

Despite the value of prenatal visits, fully one-quarter of all pregnant women receive late, little, or no care. This percentage is significantly higher for certain groups, including the very young, women over 40, black women, the poor, the unmarried, the poorly educated, and those in rural populations. As we noted in chapter 1, these are the groups most likely to be at high risk of a poor pregnancy outcome even without the burden of inadequate prenatal care. Data from 44 States suggest that 25 percent of the women who gave birth in 1977 had no prenatal care in the first trimester. Moreover, in New York City during the same year, 22 percent of all pregnant women had no prenatal care at all or none until the last trimester. In central Harlem this figure was 30 percent (*16*). Furthermore, about 70 percent of expectant mothers under age 15 receive no care during the first months of pregnancy, the period most important to fetal development; 25 percent of their babies are premature, a rate three times that for older mothers (*15*). Thus, despite the essential nature of prenatal care, it is apparent that many of the Nation's most vulnerable women do not receive such care early enough or, in some instances, at all.

Prenatal care is often associated with helping to assure the physical health of an infant. Such care is also related to the prevention of certain conditions that may later lead to mental disability and to the early detection and treatment of other mental health problems. Thus, the President's Commission on Mental Health lists comprehensive prenatal (and early infant) care first among its recommendations to implement a strategy of prevention, especially for high-risk groups such as very young mothers and those with important medical problems such as diabetes (*17*).

The health services associated with childbirth and the immediate postpartum period are also included in this set of essential services. The Panel urges that we recognize there are some women—often living in rural areas or inner cities, and typically poor—who are still not adequately linked to the health system at the time of pregnancy and childbirth. At present, about 98 percent of all births occur in hospitals; but the women who comprise the remaining 2 percent are not all women who have chosen the home birth option (*18*). Some women give birth without adequate assistance or care and have not had the advantages associated with early identification of risk factors likely to complicate the delivery and/or the health of the infant. For them and their infants, childbirth can be a risky event. Indeed, although the decline in maternal mortality in this century is due to a variety of factors, the contribution of health services surrounding childbirth to reducing such mortality is clear. Thus, we must not only increase the availability of prenatal care, but must also assure that women have access to delivery services that are appropriate to their level of risk and to their personal preferences.

Postpartum services form the final component of this set of services and complete the minimum basic set of essential services associated with childbearing. We call special attention to the 6-week postpartum checkup that typically includes family planning services.

Comprehensive Health Care to Infants and Preschool Children through Age 5 (*19*)

The value of competent, comprehensive health care for infants and young children in providing a basis for lifelong health is clear and, in the Panel's view, of equal importance to maternity care. In the area of prevention especially, children are uniquely fortunate in the range of effective preventive services available to them in these early years. Some are highlighted below.

At birth, screening tests for such conditions as phenylketonuria (PKU) and congenital hypothyroidism can detect significant health problems that, if undetected and improperly managed, can lead to serious adverse health outcomes such as mental retardation. Long-term experience with screening programs for PKU indicate the success of these programs in detecting children for whom a dietary change will mean the difference between normal functioning and mental retardation. These programs are clearly cost-effective and have proved readily feasible. The PKU program stands as a model for the development of screening services for other diseases and disorders that can be identified at birth. Similarly, recent experience with universal newborn screening for thyroid disease has demonstrated that this simple procedure is efficacious and clearly cost-effective (*20*). Screening tests, including prenatal diagnosis, are also available for the early detection of sickle cell disease. Mortality can be reduced by early detection, and therefore screening for sickle cell disease in the first year of life should be a component of every black infant's health care.

Routine neonatal care also includes intramuscular administration of vitamin K to prevent the bleeding that occasionally occurs in newborns, and instillation of an appropriate solution to the eyes to prevent serious eye infections, some leading to blindness, that might occur if the mother has gonorrhea.

Immunizations in infancy and childhood are among the safest and most effective measures for disease prevention. Widespread vaccination has eliminated smallpox and led to marked declines in the incidence of diphtheria, measles, whooping cough, polio, rubella, and tetanus.

Other forms of early intervention are also effective. For example, early detection of hearing impairment—suffered by approximately 10 percent of U.S. children—and prompt attention to an infant's communication needs dramatically reduces the serious secondary consequences of hearing loss, including possible inhibition of cognitive and language development. As a result, several expert panels have recommended that children who meet specified criteria receive full audiological assessment between 2 and 6 months of age and periodically thereafter. The importance of detecting vision defects—affecting close to 20 percent of children—is equally compelling in the preschool period.

Screening some populations of young children in urban areas for lead poisoning and tuberculosis is also of great value. Since the discovery in the mid-1950's of serious environmental endemic lead poisoning, child health professionals, long aware of the devastating effects of lead poisoning, have urged employment of the relatively simple procedures needed to sample lead in the environment and detect lead levels in individuals. Routine preschool examinations can include screening for markers of lead poisoning and, if a problem is detected, lead to appropriate management. Similarly, screening for tuberculosis is efficacious and easily performed. Although the incidence of tuberculosis has dropped considerably in the past 20 years, the disease is still common in some communities, particularly where there is overcrowding. Furthermore, new immigrants to the country have often been exposed to tuberculosis in their countries of origin.

Various measures of maturation and developmental assessment go hand in hand with screening and immunization activities. Serial measurements of height and weight, properly recorded for ease of comparison, are the most objective indicators of normal or abnormal physical growth. Failure to grow at the usual rate for a specific age, height, and body type may be the first indication of serious difficulty. For example, abnormally rapid growth in head circumference early in life may be a warning of hydrocephalus, and slow growth in head circumference may indicate failure of brain development. Other findings that deviate from the normal may also be an indication of future problems. Hypertension, which can now be recognized in infancy, may in children and adolescents occasionally be an early sign of serious renal, vascular, or endocrinologic disease. Although it is not yet known whether therapy during childhood will alter the prognosis for primary hypertension, or what the precise relationship is between childhood and adult hypertension, it is prudent to be aware of each child's status until current studies provide predictive and therapeutic direction.

Delayed development in gross motor, fine motor, adaptive, language, and personal-social areas may indicate only normal differences in rates of development or may suggest a wide variety of serious problems, some of which are amenable to intervention. No single method for testing development has been proven superior. However, careful developmental appraisal and subsequent diagnostic studies may uncover sensory defects, muscular or neurologic disease, or emotional deprivation.

Another preventive service which in the Panel's view is of enormous importance is counseling and anticipatory guidance to parents of preschool children. Elsewhere in this report, such issues as accident prevention for young children, infant stimulation, and the importance of sound nutrition in early life are discussed and their role in child health outlined. The significance of these health topics cannot be overemphasized, nor can the value of helping parents care for their children effectively be overstated.

The case for prompt, early treatment of young children is as compelling as that for primary preventive services. No preventive health examination or screening is complete unless treatment is obtained for identified problems. Indeed, the distinction between treatment and prevention at this life stage is somewhat artificial. Most significant health problems that arise in this period have lifelong consequences if not effectively managed. Untreated otitis media can evolve into conduction deafness; neglected strep infections can develop into rheumatic heart disease or nephritis; and untreated tooth decay can lead to loss of teeth. Thus, treatment services in childhood are often preventive services when viewed over the full life span.

One treatment service with major preventive implications is neonatal intensive care, a service that should be fully available to all newborns. In the past, infants born seriously ill and/or of very low birth weight often died; those who did not were at high risk of suffering deficits in both mental and physical development. With the recent introduction of neonatal intensive care, however, such risks have declined significantly. A 1980 paper developed for the OTA concluded: "...Over the past 10–15 years, or since neonatal intensive care methods have been applied, there has been a dramatic improvement in [the] survival of low-birth-weight newborns, and most of the survivors are normal. ... The widespread application of neonatal intensive care appears to have played a major part in producing the improved survival as well as the improved physical condition of very low-birth-weight infants [in recent years]." This paper also noted that rising birth rates and the high level of risk factors such as teenage pregnancy, smoking, and low socioeconomic status associated with low birth weight are likely to create an increasing need for intensive medical care of the high-risk newborn over the next decade (*21*).

The central message to be drawn from this brief survey of services in the first years of life is simple: early infancy and young childhood are critical life stages during which vulnerabilities are great and the possibilities for helpful health care interventions numerous. If a child is helped to mature through this period safely, with preventable health problems avoided, with others identified and managed as early as possible, with effective measures such as immunizations taken to avoid later health problems, and with the nurturing capacities of his or her parents developed and supported, the young person's chances for a healthy childhood and adulthood are increased dramatically.

Nonetheless, many children do not have access to the care they need. As recently as 1976, a third of all children under 10 were not properly protected against seven major childhood diseases, and in the following year rubella cases for children under 15 years increased by 63 percent, measles cases by 39 percent and whooping cough cases by 115 percent. Since then, as noted in chapter 1, these percentages have been cut significantly, due in large measure to the highly effective Childhood Immunization Initiative.

Although the immunization story is at present a hopeful one, other measures of child health status and use of health services are not so reassuring. For example, data from the EPSDT program of Medicaid demonstrate that the stereotype of children as uniformly healthy is untrue, particularly for the poor children touched by this program. The Children's Defense Fund study of EPSDT concluded:

> One thing screening data make clear is that most children screened by EPSDT are suffering from health problems and desperately need the services of EPSDT. Nationally, for every three screenings, two conditions needing followup care were found (*12*).

Common problems that were not being cared for included dental problems, low hemoglobin levels, vision difficulties, chronic upper respiratory problems, elevated lead levels in the blood, genitourinary infections, hearing problems, skin problems, parasites, orthopedic problems, and problems with the heart and circulatory system. Specific measures in selected States are especially troubling. In 1978, for example, 34 percent of the children screened in Louisiana had a vision problem, 3.5 percent of the children screened in Connecticut exhibited signs of lead poisoning, and a full 90 percent of the children examined in Mississippi had demonstrable dental problems (*14*).

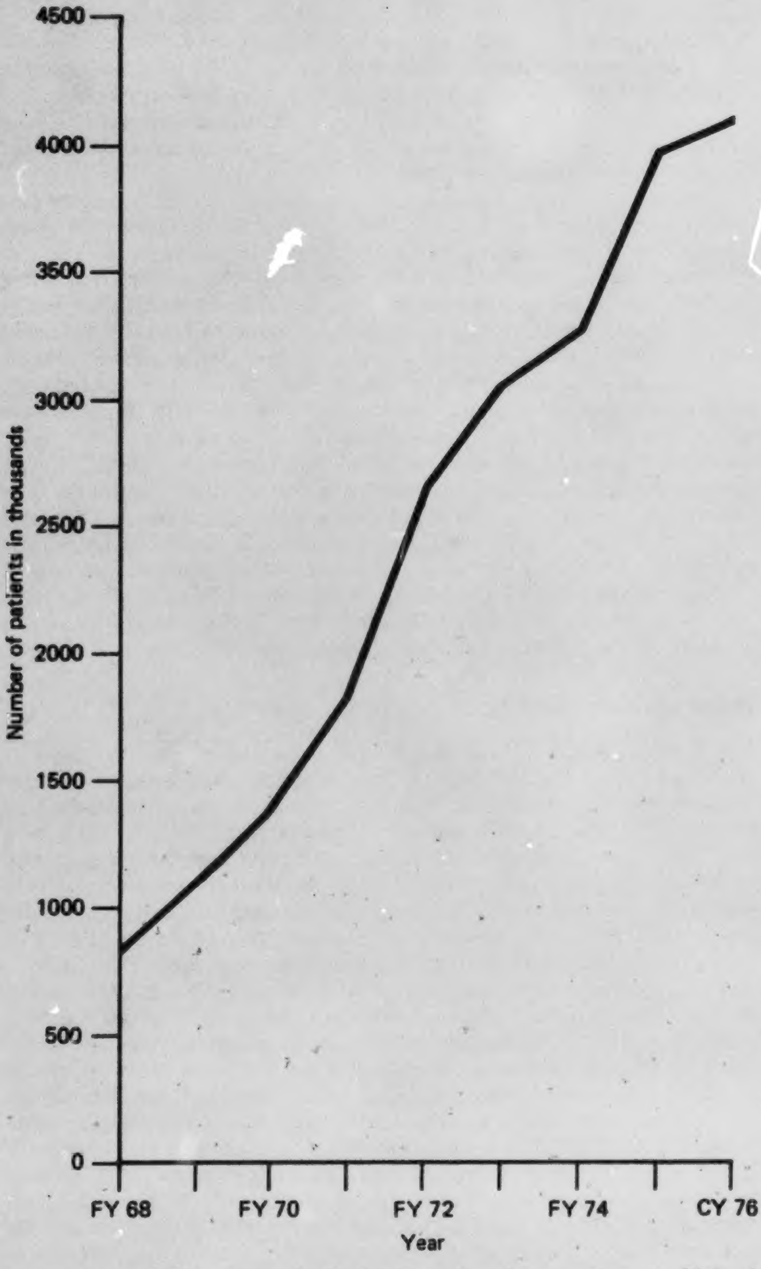
Cost-effectiveness for the cluster of services typically utilized in the first several years of life is difficult to calculate, primarily because such services are actually a combination of many individual interventions, each of which would have its own cost-effectiveness ratio. The research that would be needed to assess fully the costs of providing none of these services is neither ethical nor feasible. However, for selected individual services in these early years, such as immunizations and screening for such conditions as PKU and congenital hypothyroidism, the cost-effectiveness data are impressive; some are presented in chapter 1. Even neonatal intensive care services—with an average cost estimated to range as high as $40,000—have been judged cost-effective. The OTA report mentioned earlier concluded that neonatal intensive care is cost-effective for infants over 1,000 grams and may even be so for infants weighing less than 1,000 grams (*21*). We caution, however, that the methodological complexities of such calculations are great and that in this area as in many others, cost-benefit analyses are of limited value. More to the point is the fact that, in the aggregate, services to preschool children are low-cost items, not only in absolute terms, but also in terms of their long-term benefits to health.

Family Planning Services

It is obvious that a child whose birth is eagerly awaited has the best chance of getting a healthy start in life. A wanted child is far more likely than an unwanted one to enter a loving, nurturing home environment that encourages healthy growth and development. Similarly, a woman who welcomes her pregnancy will probably adhere to the health practices necessary to increase the chances of a successful pregnancy outcome. Few would question, therefore, that every child should be born wanted and loved; most Americans now feel that policies assuring the availability of family planning should be endorsed as a means to that end.

A voluminous body of research indicates the timing of a birth (when the mother is neither too young nor too old), adequate intervals between births, and family size limitations are closely related to better maternal and infant health. Infant mortality, low birth weight and stillbirths can be reduced through family planning (*22, 23*). For example, it has been shown that almost a third of the reduction in the U.S. infant mortality rate between 1965 and 1972 resulted from shifts in the timing and spacing of births and, hence, from individual family planning decisions (*24*). A study of low-income Maryland women found the greatest decreases in infant mortality occurred in areas that had made the most progress in serving women in need of family planning services (*25*).

Family planning can also contribute to a woman's health. Having a large number of children is frequently detrimental to a mother's health,



Patients served in organized family planning programs: United States, 1968-76 and women bearing a fifth or higher order child experience maternal mortality rates as much as twice as high as do women bearing a second, third or fourth child. Women giving birth in their teens or after the age of 35 run increased risks of death and complications such as toxemia, eclampsia, and hemorrhage. Too short an interval between births also has a deleterious effect on a woman's physical, mental, and emotional well-being (*26*).

The use of contraception to prevent unwanted pregnancy has gained wide acceptance in the United States. By 1976, 9 out of 10 married Americans were using some method of contraception or had been surgically sterilized (*27*). There was also increasing use of contraception by sexually active unmarried persons as growing numbers of young working people, teenagers, divorced and separated persons sought to prevent unintended pregnancy. With the advent of the publicly supported family planning programs, the gap in contraceptive use between rich and poor, and blacks and whites has narrowed significantly and all segments of the population have come closer to achieving their desired family size (*28*).

Despite the great value of family planning services, it is apparent that there still is an unmet need for such care. Although unwanted and mistimed childbearing has declined substantially in recent years, it still presents a serious problem for many Americans. An estimated 2.8 million unplanned pregnancies occur each year, half of them terminated by abortion (*29*). Almost 16 million women at risk of unwanted pregnancy are not receiving the health care necessary for the safe and effective use of contraception. Three million of these women have low or marginal incomes and 1.8 million are teenagers who need subsidized care (*30*).

Family planning services are essential not only to meet remaining unmet needs, but also to sustain the ability of those already practicing family planning to continue doing so. From a public policy point of view, the value of continuing and expanding family planning services through a variety of provider arrangements in both the public and private sector is indisputable. (See chapter 7.)

Service Domains of Special Priority

The second major Panel finding that emerged in the process of developing our lists of needed services is that four additional groups of services merit special attention. These include: mental health and related psychosocial services, dental services, genetic services, and services that promote access to care. Although each has unique attributes, they have in common not only their importance to health but also the fact that they are not now adequately available, especially to some of the groups most in need of them, and that they have not been accorded sufficient prominence in current views of the essential components of maternal and child health care services. By singling them out for specific discussion, the Panel hopes to strengthen the national consensus regarding their value in health promotion.

Mental Health and Related Psychosocial Services

Mental health services and services related to psychosocial issues are prominent in the lists of needed services developed by the Panel. This emphasis is based on the evidence that mental disorders and psychosocial problems are significant components of the total burden of illness in children and their families, and the fact that the profile of child health needs has shifted significantly in recent years. Whereas survival concerns and the threats posed by infectious diseases were the central focus of child health in the past, we are now confronted by a challenging blend of problems with interwoven psychological, social, environmental, and organic components.

Although precise estimates of the prevalence of mental disorders in children are difficult to make due to various methodological and definitional limitations, mental health problems in children are sufficiently common to constitute a major concern in any discussion of child health. For example (*31*):

- Surveys of general populations show that the overall prevalence of persistent and socially handicapping mental health problems in children aged 3–15 years is about 5–15 percent.
- Conduct disorders and impairments or delays in development may affect up to 10 percent of boys 7–10 years old.
- Mortality due to suicide in adolescents 15–19 years of age has increased from 3 deaths per 100,000 in 1950 to 10 deaths per 100,000 in 1977. Estimates of attempted suicide range as high as 1 out of every 1,000 adolescents.
- Psychotic disorders appear in childhood—autism, for example, occurs in about 3 or 4 children out of every 10,000.

In addition to such direct measures, an additional set of broader social indicators suggests that a large proportion of children are under significant emotional stress and at risk of developing mental disorders. For example:

- Each year, approximately 1 child per 1,000 under 4 years of age suffers serious injury initiated by parents, and about 1 in 10 of these injuries proves fatal (*31*).
- By conservative estimates, at least 2 million children have severe learning disabilities that, if neglected, can have profound mental health consequences for the child and family (*32*).
- On any given day, 20,000 youths are in some kind of criminal detention; adolescents are involved in more than half of all serious crimes reported in the United States. (*5*).
- Some 11,000 girls under 15 become pregnant and give birth each year (*30*).

In the face of such evidence, the Panel is deeply concerned that mental health and related psychosocial services be fully available and adequately valued as major components of health services directed at child health promotion. The Nation's commitment to improving and extending medical care services must be matched by equal attention to assuring that a range of high quality mental health and psychosocial services is available, including hospital-based and ambulatory mental health services, long-term psychiatric care, counseling and anticipatory guidance provided in many settings, crisis intervention, and related services. Further, special attention must be given to eliminating major gaps in services. For example, mental health services for adolescents are clearly inadequate, despite the widely shared recognition that behavioral problems—including accidents, homicide, and suicide—are among the most significant burdens in this population and in some instances are increasing.

We also call special attention to the need for closer integration of mental health and general health services for children and adolescents and indeed for the full population, particularly at the primary care level where so many child health issues are managed. This perspective is based on a growing appreciation of the inseparability of mental health and physical health. It is increasingly well recognized, for example, that the benefits to an infant of a warm and caring environment are expressed in both physical and emotional well-being; that various psychological stresses in childhood can be linked to such somatic problems as insomnia, gastrointestinal disturbances, and headaches; and that nutrition-related disorders such as anorexia nervosa are based largely in psychological and emotional difficulties. Moreover, it is apparent that the proportion of children seen in the general health care sector having behavioral, educational, or social problems is much higher than has been generally assumed. One recent study of seven primary care facilities detected at least 5 percent and as many as 15 percent of the children seen in 1 year in all but hospital teaching facilities as having such problems (33). It is also apparent that such children typically remain in the general health sector for mental health care. In chapter 7, the Panel discusses the implications of this intertwining of mental health and physical health services for the organization of care for children.

Although we focus on formal and definable professional services in that section of our report and in the discussion that follows, it is also important to recognize the great importance of personal and social support systems in maintaining mental health and preventing the development of serious mental and emotional disabilities. When we have problems, most of us initially turn for help to families, friends, neighbors, schools, religious institutions, self-help groups, and voluntary associations. Without impairing the autonomy, natural strengths, and effectiveness of these supports, public policy must be designed to enhance their ability to contribute to the mental health of children and families.

In the brief sections below, we take up the special need for mental health and related psychosocial services of children who are mentally retarded and those with serious physical handicaps or chronic illnesses, and the importance of anticipatory guidance.

Special Focus—Mental Health Services for the Mentally Retarded

Each year, an estimated 100,000 children are born who will be identified as mentally retarded sometime during their lifetime, and approximately one-third of all mentally retarded persons suffer multiple handicaps, including mental illness, epilepsy, cerebral palsy, and other disabilities.

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Some 200 known causes (and untold others) precipitate mental retardation, of which genetic defects, biological diseases, birth injuries, and psychological or social deprivation are the most common. The level of disability ranges from barely noticeable to a profound inability to think or respond to one's surroundings (*34*).

Being mentally retarded does not mean that mental illness is also present nor that it will develop; but it is also true that the incidence of emotional and mental problems is higher among the mentally retarded than among the general population. For some mentally retarded individuals—approximately 2 million of whom are 18 or under—mental health services are an essential part of the total range of services needed to maintain an optimum level of functioning. When mental illness is present, it may be acute or chronic, mild or severe. Traditionally, these people have "fallen through the cracks." They have, unfortunately, been neglected by both the mental health and mental retardation systems.

The reasons for this are complex, but include the gradual separation of the mental retardation system from the mental health system in the last 20 years; the frequent lack of knowledge of mental health professionals and primary care physicians about mental retardation; the fact that, at times, mental retardation has been confused with mental illness, leading to public misunderstandings and inappropriate services and systems; and the tendency to think that mentally retarded persons cannot benefit from various behavioral interventions. Too often, the mentally retarded child or youth is shuffled among mental health, mental retardation, and correctional institutions. Some States report that only limited services are available for mentally retarded persons in local community mental health clinics. Others note the low priority given mentally retarded persons in local clinics and the frequent referrals to State hospitals.

The Panel concurs with the President's Commission on Mental Health's Liaison Task Panel on Mental Retardation that a high priority be given to improving the delivery and accessibility of mental health services for mentally retarded persons. In particular, we urge that the National Institute of Mental Health be given special responsibility for assuring that federally funded mental health programs give adequate attention to the treatment of emotionally disturbed mentally retarded children. The implementation of the Community Mental Health Systems Act represents an ideal vehicle for this purpose.

As is the case for all families having a child with severe problems, support services to the family of mentally retarded individuals are also most important. The emotional impact for parents of having a mentally retarded child cannot be minimized. Such an experience may exacerbate basic anxieties in parents and may represent a mental health problem for which help is warranted. Their needs require a special sensitivity and understanding of the meaning of having a mentally retarded child. Many parents need help to cope with the many practical problems of raising a retarded child as well as with their own emotional reactions to this burden, especially if they are maintaining the primary responsibility of caring for their mentally retarded child (*34*).

Special Focus—Mental Health Services for Children with Serious Chronic Illnesses and Handicapping Conditions and Their Families

The importance of mental health and related psychosocial services for children with serious chronic illnesses or handicapping conditions and their families is almost self-evident. This issue is discussed here and also in chapter 8 within the broad context of increasing the coordination of services. A chronic illness or handicapping condition creates problems for the individual and the family that can often be eased and managed with appropriate help. For the child, the stresses are not just related to the specific problem (e.g., malaise, pain, or other physical symptoms or disabilities). They are also related to the frequent hospital admissions and the treatment procedures some individuals require (medical and surgical), the changes in the emotional climate of the family, and the possible limitations on peer and other social interactions. There are also pressures that relate to specific health problems. For example, a child with a seizure disorder may fear loss of consciousness or uncontrollable strange behavior; hemophiliac children must restrict their physical activity and are constantly concerned with avoiding injury; and children with chronic renal disease must handle frequent hemodialysis, possible kidney transplantation, as well as the side effects of the immunosuppressive drugs.

Counseling services play an especially critical role in the management of selected chronic illnesses. In children with diabetes, for example, emotional stress or problems—and even the ordinary pressures of daily life—can lead to noncompliance with the therapeutic regimen, manifested by omitting insulin injections, falsifying urine test reports, eating indiscriminately, not exercising, or not keeping appointments. Education and preventive psychological counseling can minimize such problems. Unless the child and family are helped to ease the pressures associated with noncompliance, there may be increased crises, need for hospitalization, and possibly other complications (*35*).

A recent study confirmed the value of counseling for chronically ill children. Each of 20 lay counselors was assigned to several families having a child with a chronic physical disorder. These counselors provided a variety of services ranging from direct counseling of the child and family to such support services as advocacy, service coordination, and transportation. At the end of the first year, an evaluation of the program revealed that "... of the 50 children in the counseled group, 33 (60 percent) showed improvement in psychological status, compared with only 17 (41 percent) of the 42 controls who were not counseled. Conversely, only 33 percent of the study children showed a worsening in [psychological status], compared with 52 percent of the controls." The physicians of the children also noted the value of the counseling programs. "Of 19 doctors, 17 observed some direct benefit from the programs to families and were able to cite specific examples: improved relationships within the family, more regular attendance at appointments, greater compliance with instructions and closer links with the school and other community agencies" (*36*).

Many of the adjustment problems faced by chronically ill and handicapped children are exacerbated by adolescence, which suggests a special need for the availability of mental and psychosocial services at this stage. In early adolescence, cognitive development has progressed sufficiently so that the future begins to assume definite shape, and the implications of chronicity become very potent. This realization can result in a variety of responses, from greater determination to adapt successfully, to depression and noncompliance with various medical regimens. Further, some conditions such as muscular dystrophy and cystic fibrosis continue to deteriorate through childhood so that by adolescence the child may be more dependent on others for basic care. This increased dependency, at a time when greater independence is expected, can be very difficult for both the handicapped child and the family.

The family often requires specific support. The problems presented to parents by a chronically handicapped child are special because they demand that the family acquire certain knowledge that other families do not need. They must learn, for example, about special diets; about financial resources and the complex processes for securing them; about how to explain to school teachers what their child can and cannot do; and—not the least important—about how to manage their own feelings, frustrations, and disappointments. The financial costs to a family, both direct and indirect, are also a source of stress. Furthermore, parents usually cannot turn to friends and neighbors for help and information, because they are not familiar with these problems or because they react adversely to the handicap.

In this connection, we also note the importance of supportive care to parents of very premature infants. Although such infants are not usually handicapped or chronically ill as discussed here, their early birth and often precarious situation in their first weeks of life put great stress on the parents that, if not eased through appropriate counseling and help with practical problems of caring for such infants, may have a negative influence on parent-infant attachment and on future parenting competence (*37*).

The need to bolster the family in these varied circumstances is great. The most important factor in determining whether handicapped children are more likely to experience emotional or behavioral problems than normal children appears to be the level of family functioning, and that can often be strengthened by appropriate supports. If, in spite of the handicap, the family is able to provide a fairly stable, supportive, caring environment for the child, he or she is less likely to develop maladaptive patterns of behavior.

Special Focus—Anticipatory Guidance

Included in our lists are a number of services labeled anticipatory guidance, long recognized as a major component of pediatric practice. The Panel singles out this service for special mention because, although it is often thought of as a "soft service" (i.e., difficult to define precisely), we share the widespread consensus that anticipatory guidance is an essential part of the health services needed by mothers and children. Although the

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specific topics vary by age of the child, the parents' need for clear and reliable information regarding various child-rearing issues and for a sympathetic and informed advisor when problems arise remains great. Indeed, many pediatricians in practice will report that such guidance and counseling to parents is one of the most important components of the care they offer. In the course of routine well-child care, for example, parents frequently require information regarding infant feeding, minor behavior problems, and general growth and development. Such issues are typically handled by the provision and exchange of information leading to enhanced parent understanding, confidence, and competence. Such guidance is especially helpful to parents in handling temperamental differences in children, unrealistic expectations, and unfounded anxieties. Anticipatory guidance to parents regarding, for example, accident prevention and home safety are essential components of prevention-oriented care for young families. Similarly, in the practice of obstetrics, it is difficult to overemphasize the value of guidance to a pregnant woman about, for example, how to recognize the onset of labor, the use of medications during pregnancy, and ways to avoid exposure to various environmental risks (*38, 39*). In our view, such services are critical components of care, and we urge that research on such services be increased so their effectiveness can be better documented. We note, however, that to establish the value of such services will require sustained attention to developing new outcome measures appropriate to such psychosocial interventions. This issue is taken up at greater length in chapter 13.

Dental Services

Dental caries is the primary cause of tooth loss through young adulthood, and 55 percent of children in junior high school and 65 percent of high school students have periodontal disease. According to the American Dental Association, by age 17, eight or nine permanent teeth have decayed, been filled, or are missing and 97 percent of this country's poor children need dental care. By age 35, the average American has lost 5 teeth and has 11 more attacked by caries. Thirty-three percent of the elementary school children aged 6–11 in the United States have two or more decayed teeth. In addition, for this same age group, the total Decayed, Missing, Filled (DMF) Index for permanent teeth is 1.7 per child; the incidence and prevalence of caries as measured by DMF for adolescents (age 12–17) rises about 1.0 DMF tooth per year with the incidence of caries in adolescents being twice that of younger children. With regard to periodontal disease—which is a progressive, destructive lesion of the dental supporting apparatus and the primary cause of tooth loss in persons over 35—results of the Health and Nutrition Examination Surveys conducted in 1963 and the early 1970's indicated that gingival and periodontal disease treatment and decay treatment constitute the major areas of dental treatment needs when all ages and sexes are compared on an aggregate basis. Moreover, all agree that it may begin in childhood or at puberty. Both caries and periodontal disease are progressive illnesses that ultimately result in the loss of teeth when left untreated.

The most distressing aspect of these prevalent problems is that most oral diseases are preventable; the oral health of adults is determined to a large extent by the preventive and treatment services they receive as children and by the oral hygiene practices and dietary habits they develop during childhood. Principal strategies to promote oral health of children, and thus the full population over time, include fluoridation of water supplies; the use of a variety of fluoride supplements such as fluoride tablets, mouthrinses, self-applied fluorides, and fluoride toothpastes (see chapter 2); limiting the availability to children of foods and snacks that encourage tooth decay (see chapter 4); education about oral health generally and individual responsibility in particular for maintaining oral health; and a variety of professional dental services embracing preventive, therapeutic, and restorative care (*40–42*).

It is apparent that none of these strategies are being pursued adequately. The picture is particularly discouraging with respect to the availability and use of professional dental services, including those associated with the proper use of various fluoride supplements. For example, the United States National Commission on the International Year of the Child, in its 1980 report to the President, stated that 47 percent of children in the United States under the age of 12 have never been to a dentist for care (*43*). Many factors in both the public and private sectors contribute to this dismal figure including:

- Lack of a national focus on the promotion of dental health.
- Lack of systems to assure followup dental treatment for children screened in the major federally supported screening program. Under the current EPSDT program, only 25 percent of those who are screened are actually referred for dental treatment and only about 20 percent of those eligible under the program are actually screened (*44*).
- Lack of inclusion of dental services in major health plans, especially the lack of federally required dental benefits in Medicaid. Indeed, at present, Medicaid dental benefits that exist at State initiative are often being reduced.
- Lack of clarification of the role of hospitals, neighborhood health centers, public health clinics, and dental school clinics in the delivery of comprehensive dental services.

In chapter 7, we recommend a program for delivery of selected dental services to all school-age children. Given the extraordinary unmet need in the dental area, and the clear effectiveness of preventive dental services, the Panel assigns a very high priority to this proposal.

Dental treatment has been cited as one of the greatest unmet health needs of the Nation's handicapped children, particularly those in custodial institutions. Three groups in special need of care are the mentally handicapped, physically handicapped, and the medically compromised—those with diabetes, arthritis, epilepsy, heart conditions, and hemophilia. It has been estimated that only 10–25 percent of the Nation's practicing dentists are willing to treat certain kinds of handicapped patients in the private office setting. Yet, in many cases, even they are unable to do so either because of the seriousness of the handicapping condition, or other reasons such as architectural barriers (*42*). Established institutional facilities such as hospitals and dental school clinics should play a greater role in provision of dental services for severely handicapped children and youth.

Genetic Services

Genetic diseases are among the most widespread and burdensome afflictions confronting contemporary society. An estimated 6 percent of the population, or 12 million Americans, suffer from diseases involving disorders of the hereditary material, the genes and chromosomes, and genetic disorders account for a significant percentage of the severe mental retardation in the United States. Genetic disorders are present in nearly 5 percent of all live births and each married couple in the United States has a 3-percent chance of having a child afflicted with a genetic disorder (*45, 46*).

According to the National Genetics Foundation, over 2,000 genetic diseases have been identified. The incidence of these conditions varies. For example, Tay-Sachs, which inevitably and painfully kills children afflicted with the disease by age 5, is rare among the general population but relatively common among Eastern European Jews; the incidence of spina bifida (open spine defects) and anencephalia (absence of a brain) is estimated at 2 per 1,000 births; and the incidence of Down's syndrome (mongolism) is closely correlated with the age of the mother and is estimated to occur in 1 out of 800 infants born to women age 30, 1 out of 280 infants born to women age 35, and 1 out of 40 infants born to women aged 40–44 (*40, 47, 48*).

According to the *Second Annual Report on the Administration of the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act* issued by the National Institutes of Health:

> The costs—both economic and social—of genetic disease are enormous. The cost to society of caring for those suffering from Down's syndrome, for example, which is manifest by mental retardation and which has an estimated frequency of one in 1,000 births, is approximately $1.7 billion annually. On the other hand, the estimated medical bill for a child with Tay-Sachs disease ranges from $20,000 to $40,000 per year for the 3 to 5 year average life span of such a child. Care for all Huntington's disease patients ranges between $110 and $125 million annually, and treatment for a hemophilia patient averages about $12,000 per year. However extreme the financial cost may be, it pales in comparison to the emotional impact on affected individuals and families (*45*).

In the face of this burden of genetic diseases, a range of services has evolved, often called "genetic" services, that typically includes genetic screening and testing, counseling, and treatment.

Amniocentesis is an important component of screening and diagnostic services. About 100 of the 2,000 genetic disorders that have been identified can be diagnosed in a fetus during the second trimester of pregnancy (*15*). A pregnant woman at risk of carrying a fetus afflicted with a serious genetic disorder because she has delivered a previous affected child, has been diagnosed as a carrier, or is over 35 (and so runs a greater than average risk of bearing a child with Down's syndrome) may undergo testing through amniocentesis between the 16th and 18th weeks of pregnancy. In the small number of cases where a severe abnormality is found, the option of terminating the pregnancy may be considered.

Another recent advance in the prenatal detection of genetic disorders has resulted from the high correlation between elevated levels of alpha fetoprotein (AFP—an important protein in the developing fetus) in the maternal bloodstream and severe neural tube defects in the fetus. Serum AFP levels can be detected by a simple maternal blood test followed by laboratory analysis. Tests finding elevated AFP levels are then followed by amniocentesis to confirm the presence of a fetal defect. Although AFP is used extensively as a screening technique in the United Kingdom, the technology is still in the developmental stages in the United States. The Food and Drug Administration currently is considering approving limited domestic use of AFP testing with restrictions designed to assure the procedure's efficiency and safety. It is critically important to the responsible use of AFP testing that standards and procedures be established to guide laboratories in their analysis of maternal serum as well as health providers in their special responsibilities in offering and providing the test. It is distinctly possible that, with rapid advances in technology, additional simple and reliable tests for the detection of many genetic disorders could be readily available in the foreseeable future.

Genetic counseling is an important component of genetic services, and can be defined as a communication process that attempts to help the affected individual or family to (1) comprehend the medical facts regarding a genetic disorder, including the diagnosis, probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the alternatives for dealing with the risk of recurrence; (4) choose the course of action that seems appropriate in view of the risk, the family's goals and ethical and religious standards, and to act in accordance with that decision; and (5) to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. The range of problems for which counseling is provided is broad. Included are disorders resulting from simple gene abnormalities, multifactorial interactions, and chromosomal defects. Many conditions for which genetic counseling is provided will be less well defined genetically and include recurrent spontaneous abortion, multiple malformation syndromes, or unclassified mental retardation. Other issues include questions about the consequences of consanguinity, premarital counseling, genetic evaluation of children placed for adoption, and exposure to drugs or radiation before and during pregnancy (*49*).

Because of the health, financial, and emotional benefits of the emerging field of genetic services to both individual families and society as a whole, sufficient facilities, programs, and adequately trained personnel must be available to accommodate the increasing need and demand for services. In recognition of the compelling case for increased genetic services, Congress in 1975 enacted the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs and Genetic Disease Act (changed in 1978 to the National Genetic Diseases Act), Title XI of the Public Health Services Act, which authorized $30 million a year to pay for statewide programs of amniocentesis, genetic screening, counseling and treatment. However, the $8 million funding of this program in 1980 still falls far short of the $30 million authorized by Congress and of the $15 million estimated by the National March of Dimes Birth Defects Foundation to be necessary to provide adequate prenatal genetic screening services for all those needing them (*50*). Without the State programs and cytogenetic lab facilities that were expected to be funded under this act, services cannot be extended to many in need.

Data on the use of amniocentesis suggest how great such unmet need might be. Although no definitive national data exist, it has been estimated that only 20,000 of the 150,000 pregnant women over age 35 who each year are at high risk of bearing a child afflicted with Down's syndrome receive amniocentesis (*51*). There are many reasons for such low utilization, including costs of the procedure and the limited number of facilities and personnel able to perform it. Many couples remain unaware of the incidence of genetic diseases and of the availability of genetic services, including amniocentesis. There has been no major nationwide public education campaign on the topic, and many publicly funded programs and private physicians do not systematically provide women of childbearing age with information about genetic diseases and genetic services.

Access-Related Services

Early in this chapter, we noted that one of the reasons that the services identified in the lists are not adequately available to mothers and children is that a variety of barriers exist that limit the accessibility of such services. To increase access, this report advocates broad changes in the organization and financing of services, including an increased commitment to strengthen and expand a set of specific services whose primary purpose is to facilitate entry into the health system—the first step in obtaining needed health services. The significance of the access problem is underscored by the data presented in this chapter and in chapter 1 documenting the fact that some children have never seen a doctor, that major gaps in the use of needed services continue to exist among various groups, and that even vitally important services such as prenatal care are not fully accessible, particularly to populations at special risk. The Panel's proposal in chapter 7 to increase home-visiting services is one major way to help change this picture. Here we highlight the value of four other types of access-related services: outreach, transportation, telephone access, and child care arrangements (*52*).

Outreach

For many families, health services are so inaccessible— geographically or for other reasons—that they cannot make use of them without help. Some parents still do not know or understand what benefits early health care would bring them and their children. This problem is acute among parents with little education and among some from other countries where health care is organized differently. Well-educated, affluent parents, too, can be unsure whether a child's behavior or symptoms are normal or whether they require professional attention. They are more likely, however, to have family doctors or pediatricians whom they can call and from whom they receive advice, assurance, or an appointment.

Sometimes health care programs must do more than provide an open door. They must take the initiative to find, educate, and help bring in mothers and children to receive care. In recent years especially, health programs serving rural and low-income urban populations have found that the use of trained outreach workers can solve many problems of access. The experience of the Columbia Point Neighborhood Health Center in Boston, Massachusetts, is a good case in point. Located in a low-income housing area, one of its objectives was to encourage residents who had previously not used health services to seek medical care regularly and promptly. Outreach workers were a central part of the strategy. Although success cannot be attributed to the outreach and education efforts alone, after 2 years of the program, a substantially higher proportion of residents felt that general, preventive measures were important and showed an increasing disposition to bring to the attention of health center staff symptoms at an earlier stage when they were less painful or disruptive. The proportion of families who reported that they or someone in their family had postponed medical care in the preceding 6 months declined from 23 to 10 percent.

The American Medical Association, in its Statement on Health Outreach, cites the variety of ways in which outreach workers, particularly those who live in the area served by a health care program, can improve services. Outreach workers:

- Tend to enhance professional standards of practice because such personnel can free physicians, nurses, dentists, and other health professionals to better utilize the time for which they are trained and extend the scope of services to a larger patient population.
- Provide an additional source of manpower to meet community needs, especially in those areas where there is a shortage of professional health staff.
- Obviate many of the traditional problems of understanding and communication in getting health services to those in need.
- Assist the professional staff in becoming more responsive and accountable to the community served.
- Provide meaningful jobs and, as a result, benefit the community economically and socially.

Principles that enhance the effectiveness of outreach have been enumerated by the Children's Defense Fund. They note that personal contact is the most effective form of outreach, and that outreach is best performed by trained personnel who share or are sensitive to the background of the people being served. It should be conducted in a variety of places in a community, be supplemented and reinforced by training nonhealth personnel, and should link people to a system of care.

Transportation

Sometimes health care providers and facilities are only theoretically available. Long distances or high costs in getting to a source of care can be major barriers to obtaining needed health services. For the poor, distance appears to be a significant deterrent to seeking preventive care (*53*). Where health care services exist but are difficult or impossible to reach because people lack adequate transportation, transportation services are a needed component of the health system. They can be provided or arranged by (a) modifying existing public transportation schedules and routes to efficiently link patients and health care facilities, (b) reimbursing families or patients for transportation they can find themselves but cannot afford, (c) contracting with other agencies to provide transportation to health services, or (d) developing a program-run transportation system.

Telephone Access

The ability to obtain information and advice concerning health problems over the telephone is critical. In an emergency, it may be a matter of life or death. In less urgent situations, the family that can easily and quickly reach a doctor by telephone is more likely to seek information about a health problem early in its course. This may prevent the problem from becoming serious, and helps parents use health resources most appropriately.

Telephone access is particularly important for parents. It is well known that pediatricians in private practice spend much time advising parents on the telephone. This, however, is largely a privilege of the middle- or upper-class parent. It is accepted practice for these mothers to phone in and report a fever, a rash, or other troubling symptoms and receive guidance about what to do. Such access is rarely available to families of lower income. Although most group practices have some kind of telephone access, its absence in the clinics and outpatient departments serving the poor is a common byproduct of fragmented, episodic, crisis-oriented care.

The vast majority of poor and minority children, in fact, have no effective access to telephone advice at all. In 1974, 94 percent of the black children and 88 percent of the children with incomes of less than $5,000 had no telephone contacts with health care providers during the year, compared with 75 percent and 73 percent of the white and high-income children, respectively (*54*).

Several studies indicate the feasibility of making telephone advice more readily available. In one prepaid practice, for example, aides were trained to provide appropriate telephone advice or referral for calls about children's illnesses. Results showed that parents were very satisfied on the whole, the bulk of problems were resolved by phone, and quality of care was generally good (*55*). Equally successful was a telephone "hot line," installed in a diabetic clinic at the University of California Medical Center to provide information and medical advice to patients and to fill prescriptions. It was estimated to have saved 2,300 patient visits for medications alone during a 2-year period, with improved levels of patient health (*56*).

Such data undergird the Panel's view that there should be some time during the day when families can consult over the telephone about general areas of concern with health professionals who are able to provide the caller with appropriate instructions. Whenever possible, the medical personnel giving telephone advice in nonemergency situations should have a continuing relationship with the caller. In addition, every community should have 24-hour, 7-day-a-week access for emergencies, and day and evening access for acute health needs.

Care for Other Children

Many parents who need to bring a child in for care have other children at home. Babysitters are normally hard to find during the day when older children are in school. Even if one is available, some people cannot afford to pay a sitter. In the evenings, when a family member could take care of other children, health care facilities are usually not open. As a result, many parents either put off getting care except in acute or emergency situations or bring all of the children to the clinic. The burden of taking several small children on public transportation and waiting with them, particularly when one of the children is sick, is stressful for everyone involved—parents, children, people giving care, and other people waiting to receive care. Sometimes a simple thing like the lack of child care—especially in addition to other difficulties—prevents families from getting health care altogether.

In situations where the lack of care for other children is one of the factors preventing families from getting health care, the health care programs themselves must intervene on behalf of their patients. This can be accomplished in several ways:

- Providing a child-care room right at the health facility where children can spend the waiting time pleasantly without disturbing others.
- Paying for babysitters the families themselves find.
- Forming or arranging with a group of babysitters in the community to go to homes as needed. These can be paid for by the family or the health program.

The experience of many programs suggests that the most easily managed and most helpful arrangement is to have a playroom as part of the clinic facilities—provided that it is realistic, in terms of location and transportation, for the mother to bring the children along. Such a playroom should be under the supervision of a person trained to manage small children. Whatever provisions are made for the other children, the mother should be told about them specifically before she comes to the clinic.

A Board on Health Services Standards

The third major finding of the Panel in the area of needed services involves the creation of a new mechanism to serve a variety of functions aimed at improving the content, quality, and availability of health services for mothers and children. We refer to this mechanism as the Board on Health Services Standards, although as we note below, it could be a collection or consortium of existing organizations and activities rather than a newly created entity.

Many services we have identified as "needed" are not now available and utilized to an extent consistent with their potential to improve health and prevent disease and disability. Examples include counseling services, health education, various nutrition services, and access-related activities such as outreach. One reason for the relative inaccessibility and underutilization of these services is that public and private third-party payers are reluctant to finance them, in part because of the nature of the services themselves. They tend to be difficult to define precisely, and—in greater measure than is true for medical services—their effectiveness appears closely related to the circumstances under which they are provided, by whom, and in relation to what other services. They also seem to raise more questions than traditional medical services about how to measure and assure quality, and how to prevent fraud and abuse. Given this situation, the Panel found itself facing the following problem: we have found that these services are important, even essential to promoting maternal and child health, and that more people should have access to them without financial barriers. We have also found these services are not adequately available or used. Given such factors, should we simply recommend that third-party payers offer to cover these services, and hope for the best? If we were to make such a blanket recommendation, we suspect it might not be implemented for the reasons already stated. Even if it were, and more people presumably received the services, there would still be inadequate information on the effectiveness of such services and on the circumstances under which they are best provided; there would be no additional information to aid in controlling quality or protecting against abuse, and no continuing evaluation of efficacy. And the cost of financing such services might well be unacceptable because information on how to offer the services economically would still be lacking.

We have chosen instead a more cautious approach that we believe represents a constructive, long-term solution to a difficult set of problems. *We recommend that a Board on Health Services Standards be created—or existing institutions strengthened, better coordinated, or perhaps even consolidated—to perform the following functions:*

1. Review and continually refine our understanding of what health services should be available to mothers and children in light of new knowledge and changing health problems.
2. Provide information and guidance to all third-party payers, purchasers of health insurance, and others (including professional standards review organizations and health planning groups) regarding the efficacy, effectiveness, and appropriate use of a given service or sets of services, and the circumstances under which such services should be financed, taking into account considerations of quality, cost, availability, accessibility, and appropriate utilization.
3. Provide information to all third-party payers regarding the likely

effects of their payment policies and practices on the availability of needed services, professional personnel, facilities, and other components of the health care system. (This particular function is discussed in more detail in chapter 9.)

The Panel is aware that there are currently a number of groups in existence that perform some of these functions. For example:

- The National Center for Health Care Technology (NCHCT) has a broad mandate to provide advice on virtually all of these intertwined issues of services, including their assessment, use, and appropriate reimbursement.
- The research supported by the National Institutes of Health (NIH); the Alcohol, Drug Abuse, and Mental Health Administration; the Health Services Administration; and the consensus conferences of NIH especially contribute understanding about the safety, efficacy, and appropriate use of specific procedures.
- The research supported by the National Center for Health Services Research (NCHSR) and the Health Care Financing Administration (HCFA) contributes information on many health system components such as manpower, organizational settings, and payment practices, and relate such factors not only to each other but also to specific health services.
- The U.S. Congress' Office of Technology Assessment provides useful guidance not only on general principles of technology assessment but also on the costs, risks, and benefits of specific technologies and the policy problems posed by them.

The problem with these efforts from the Panel's perspective is that they rarely take up services in the domain of primary care for children and pregnant women. The fragmentation and often *ad hoc* nature of these efforts limits their capacity to develop broadly applicable norms and standards of reimbursement or to provide the systematic guidance over time to third-party payers that is so urgently needed. Further, we find that these various activities are not sufficiently well supported or integrated to provide ongoing assessment of health care practices. Consequently, their impact on shaping or redirecting existing payment practices has been limited. The National Center for Health Care Technology comes closest in stated mandate to meeting this general need, but, among other things, its inadequate funding (about $3 million in 1979) circumscribes its value considerably. The Panel also believes that these general assessment functions will best be served by a body that is not exclusively governmental.

A clear indication of the inadequacy of the present array of institutions is the recent proposal to create a National Professional Mental Health Services Commission through an amendment to Title XI of the Social Security Act. This Commission would be charged with, among other things, assessing what is known about the safety, efficacy, and appropriate use of various treatments for specific mental health problems, reviewing the relationship of various professionals and settings to the effects of selected interventions, and then recommending reimbursement policies to the Secretary of the Department of Health and Human Services (DHHS) for such services.

In our view, the time has come to systematize and draw together these many bits and pieces into a permanent, well-financed, prestigious and independent institution capable of providing expert guidance on how both the private and the public sectors can promote and finance the health services needed by mothers and children and indeed all Americans.

Although the Panel's recommendation arises from its concern about improving maternal and child health service, we believe the issues that the Board would have to address cannot over the long term be separated by categories of services or beneficiaries. We therefore believe that unless the Board is established with an unequivocal mandate to perform the functions we believe are essential to improve maternal and child health, it might very well concentrate primarily on high technology and very expensive interventions, in the hope of making some early dramatic contributions to what are conventionally seen as the most pressing cost containment problems. Issues such as the efficacy of home visits to pregnant women and infants under nurse supervision, or counseling aimed at accident prevention or compliance with prescribed regimens, which are of enormous importance in the care of pregnant women and children, might not be reached for many years. We therefore consider it absolutely essential that the Board either be mandated to begin its work with services important to improving maternal and child health, or that a definable and significant portion of the Board's resources be allocated to this function.

With regard to the structure of the Board, we outline several essential attributes:

1. The Board should have the capacity to draw on the relevant competence of a number of agencies already performing some parts of the functions we are proposing. Several of the most significant are noted above.
2. For maximum credibility and acceptability, the Board should have considerable independence from special interest groups of all kinds, and probably from government as well. If it is to draw on all existing sources of talent and expertise, conduct its own health services research as needed to develop guidelines and advice, and be sufficiently influential to accomplish the ambitious mandate we propose, the Board should be established in a manner and at a level that would give it a great deal of both independence and prestige.
3. The membership of the Board should be broadly constituted and include both experts in various aspects of health care and citizen-consumer advocates. Board members could be exclusively nongovernmental, or could include several governmental representatives, such as the Surgeon General and the Administrator of HCFA. The Board could be appointed by the President or the Secretary of DHHS, or the power of appointment could be shared among several individuals or institutions.
4. We believe the authority of the Board must ultimately derive from the quality of its findings. Although it would theoretically be possible to make the advice of the Board binding, at least on public third-party payers, we believe that this kind of authority would not be considered acceptable in this instance. We suggest

that the guidelines and recommendations of the Board be advisory, although it will be important to incorporate into the Board's mandate certain functions that would create some pressures that would make it difficult, especially for public third-party payers, to disregard the Board's advice totally. For example, the Administrator of HCFA could be required to make a public response to the Secretary of DHHS and the Congress in those instances in which HCFA decides not to follow the recommendations of the Board regarding the financing of a given service. (Additional discussion of the reimbursement practices of HCFA is in chapter 11.)

5. The Board must have resources adequate to its charge. The dismal funding experience of groups such as NCHSR and NCHCT suggests the normal appropriations process is unlikely to produce even a modest portion of the needed resources. An untapped and obvious source of funds is in the hands of third-party payers. The Panel proposes that a small percent—perhaps less than 1 percent—of the expenditures of the major third-party payers be used to finance the Board for the purposes stated. The logic is that the institutions currently financing the bulk of health services have the most need of information regarding, for example, the efficacy of the procedures they pay for, the circumstances that provide for adequate quality and efficiency, and the effects on health services of various provider arrangements. The Board might also be set up in a way that permits it to receive private funds.

We recommend as a very high priority that the Secretary of the Department of Health and Human Services convene an ad hoc group as soon as possible, in consultation with the appropriate congressional committees, the Assistant Secretary for Health, and the Administrator of HCFA, to outline the precise nature, composition, and authority of the Board within the broad guidelines we have outlined, and, that the Congress act rapidly to establish the Board. It might also be appropriate to ask the Institute of Medicine (IOM) to consider this matter and make recommendations. Indeed, the IOM might be a logical sponsor or home for the Board.

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CHAPTER 6

IMPROVING THE ORGANIZATION OF HEALTH SERVICES

Primary care for children and pregnant women is currently provided under a wide variety of structural and organizational arrangements, which range from private physicians' offices to the public schools, and include health department and hospital clinics, as well as community health centers and health maintenance organizations (HMO's).

The diversity of current arrangements has advantages and drawbacks. Such pluralism means freedom of choice for both consumer and provider in most communities, is likely to stimulate innovation in the delivery of primary care, and may help to perfect current modes of delivery (*1*). For these reasons, our Panel considers pluralism and diversity in delivery arrangements an essential ingredient of a strong maternal and child health policy. However, many children and pregnant women still do not receive the services they need most, and many types of provider arrangements are not organized to provide services as effectively as they might. To deal with such problems, we advocate organizational changes designed to strengthen individual provider arrangements and increase the coherence of provider relationships.

In the Panel's view, effective provision and utilization of modern primary health care for children and pregnant women must include access to a broad array of services, provided over time and in a variety of contexts by professionals in a number of different disciplines and with a wide range of skills. It is because only a small proportion of primary care is currently delivered through organizational arrangements that can make available such care, that the Panel is advocating far-reaching changes in the organization of provider arrangements.

The element of organization facilitates comprehensive, integrated primary health care in settings which encourage continuity; collaboration with parents and other family members; coordination of primary care with needed secondary and tertiary services; linkages with other systems serving children, such as social services and schools; systematic outreach efforts to make certain services available where people already are, and other techniques to remove or reduce access barriers.

Our Panel reviewed the need for and benefits from a greater degree of organization in the delivery of maternal and child health services with full recognition that many families, many children, and many pregnant women are faring well in health care arrangements which are not highly organized, and which are not always a gateway to a comprehensive array of services. Furthermore, we realize that many consumers and providers fear a greater degree of organization might mean less personalized care, while administrators and policymakers are concerned that more organized care may be accompanied by higher per visit costs.

We are aware that many observers have concluded that a more coherent and efficient organization of services can best be achieved by funneling public funds exclusively through one or two types of provider arrangements that have been determined to work best. There are also many who believe unsolved problems of access and inadequate care are limited to a few readily definable populations, and that any changes should focus only on these populations of the very poor, persons living in remote rural areas or in the midst of urban ghettos, and families characterized by a high degree of disorganization.

After extensive deliberations, which took account of the nature of unmet needs, where they are found, and of successful and unsuccessful efforts to meet those needs, the Panel concluded that:

- American communities vary so widely in their needs and resources, and prize so highly the diversity of their own ways of solving problems, that it is neither feasible nor wise to attempt to move the Nation toward one standard way of delivering health services to mothers and children.
- Specific attributes of organization that should be encouraged include those that promote continuity in the relationship between the provider and the family and patient, along with those that promote economy of operation.
- The effective organization and structuring of services is most important for families with handicapped, chronically ill or severely ill children; for pregnant women who for social or medical reasons are at high risk; for low-income families, who have greater needs for health and related services and fewer resources to negotiate their way around a complicated maze of fragmented health services; and for those families and individuals who have special problems which result in greater than average needs for a broad range of easily accessible services.
- Since these categories of families include about one-fifth of all children and pregnant women at any one time, and between one-fourth and one-third over a period of a decade *(2–5)*, the need for more highly organized primary care is not circumscribed, but spread widely throughout the population.
- Changes in the organization, financing and structuring of services are the most promising avenue to reaching all those with unmet needs; they are more likely to be effective than attempts to motivate people to surmount barriers which make care inaccessible and unresponsive to their needs. An analysis of access barriers to child health services undertaken for the Select Panel concludes that provider and system features are critical in determining

patterns of utilization, and that most measures of utilization "can be predicted as well from information about the individual's usual source of health care as from information about the individual's socioeconomic status and attitudes" (*6*).

Our approach to the organization of health services for mothers and children, then, is based on the shared conviction that the pluralism and diversity of the health services delivery system in the U.S. should continue and that it is and will remain compatible with a commitment to reach all children and mothers with the health services they need, as long as:

- A significant proportion of those providing primary care to pregnant women and to children incorporate into their delivery arrangements those attributes that improve the accessibility and effectiveness of a broad array of services.
- All children and pregnant women have access to provider arrangements which incorporate these attributes.
- There are systematic ways of assuring the availability and accessibility of all needed services to all children and pregnant women.

We are fully aware that diversity, so appealing in theory, is often a mixed blessing in practice. Health departments that have struggled, woefully underfinanced, to provide a well baby clinic here, a V.D. clinic there, immunizations and family planning on other days and in other places, are dismayed to find new sources of Federal funds for comprehensive health centers being funneled to a hospital or community group two blocks away. Pediatricians in private practice, their numbers increasing as the numbers of children in their community decrease, are appalled to learn of a new Federal or foundation grant to the local school board to train and employ nurse practitioners to provide comprehensive primary care in local elementary schools. And a community group is mystified at how so much money for health services can come into their area while the children most in need of continuing health supervision still have their only contacts with the health system through an occasional trip to the hospital emergency room.

But diversity does not have to mean chaos, gaps, or waste. The organization of primary care may differ fundamentally between Denver and Cleveland, and between an Iowa county and a Mississippi county. What matters is that in each, appropriate services are available—under any combination of provider arrangements—and that there are responsible authorities to assure that resources are allocated in ways that will make needed services accessible to all.

In the remainder of this chapter, we describe the attributes which we have identified as important components of effective primary care provider arrangements, and examine the specific ways that various provider arrangements should be strengthened.

In chapter 7 we discuss several issues that cut across a variety of provider arrangements, and which have important implications for the organization of health services for mothers and children.

In chapter 8 we present our conclusions and recommendations regarding the organization of services to assure that needed health services will be available to certain population groups with special needs and special access problems.

PROVIDER ARRANGEMENTS

In reviewing the broad array of provider arrangements successful in providing needed primary health care services to children and pregnant women, we identified nine characteristics that seem to be important to their success. We believe *these nine attributes of primary care units are so important, especially to populations at greatest risk, that—over time—they should be incorporated into all primary care settings.* They include comprehensive services, accessibility, capacity for outreach, coordination of services, continuity of care, appropriate personnel arrangements, accountability, consumer participation, and partnership with parents, as detailed below.

Comprehensive Services

Primary care units should offer a broad range of health services, psychological and social as well as medical. The primary care unit should be able to meet the great majority of the health needs of the population it serves, whether pregnant women, infants and children, or whole families. The services available should encompass preventive, acute, and curative care; management of long-term illness; the counseling of parents, children, and adolescents regarding psychosocial problems and other elements of health maintenance, promotion, and protection; and active efforts to build on the family's strengths and resources as well as to help it cope with problems and vulnerabilities. It should also include well-established and well-functioning links to sources of secondary and tertiary care.

Accessibility

Primary care units should be accessible in terms of location, transportation, absence of psychological barriers, and hours during which services are either provided or arranged for. The primary care unit must be reachable at all times, either directly or through a reliable arrangement known to the families served and systematically linked to the unit. The physical location of the primary source of care, available transportation, hours of service, and the circumstances in which care is provided must make it conveniently accessible to actual and potential users, and must be responsive to their needs.

Capacity for Outreach

Primary care units should have a capacity to reach out into the community they serve, so as to eliminate or minimize economic, geographic, social, cultural and language barriers to the appropriate use of health services. Outreach is especially important for primary care units serving low-income persons and other population groups that have not been effectively reached by the health system in the past. Outreach can be provided directly by the primary care unit through such mechanisms as outreach workers and home visitors. Small primary care units can provide outreach indirectly in cooperation with local community organizations and agencies.

Coordination of Services

Primary care units should be the place and the mechanism for coordinating all health services needed by an individual or family, through a working partnership among a variety of health professionals, active collaboration with patients and their families, and a strong relationship with other service systems in the community, such as the schools and the welfare system. The primary care unit should coordinate all elements of the patient's care, including that provided by other health professionals and institutions, and the participation of other agencies and providers, including those from the welfare, correctional, and educational systems. This involves referrals, the exchange of information with other providers of service, and explanations and exchanges with patients or families to achieve a greater understanding, and modifications as indicated, of treatment plans or supportive services.

The intensity of the need for coordination, and the amount of time, energy and skill required, varies with the complexity of the individual's situation. For the child or pregnant woman with complicated problems, a primary care unit must act as—or provide for—a case manager. For less complex situations, the need is for a greatly heightened awareness, and the willingness and capability to act on such awareness, of the fact that each child's and pregnant woman's health is determined by factors that extend well beyond the health system.

The partnership that our concept of the primary care unit implies among physicians, nurses, dentists, social workers, nutritionists, psychologists, and other health, education and social service professionals, and community workers, can be achieved when all of them work together in one building and for a single institution, but that is not the only way. A pediatrician, nurse practitioner, and office secretary can together create a network that reaches far beyond their office; theirs becomes a primary care unit without walls when they know how to mobilize the services their patients need, be they home visitors, social services, diagnostic specialists, or mental health consultation. They join with other professionals and advocates in efforts to establish the services that are missing. The primary care unit, regardless of size or composition, should have connections to the schools and social agencies that for some children can be as important as the connection between the primary care unit and the hospital.

Continuity of Care

Primary care units should encourage a strong relationship, over time, between the patient and family and a single practitioner or small group of *practitioners, who can orchestrate all the disparate parts of the care needed by a patient or family.* The importance of providing continuous and comprehensive primary care has been underlined by the American Academy of Pediatrics and others. The Panel joins with the Academy in advocating that every child at birth and every pregnant woman should have a source of continuing care (sometimes referred to as a "medical home") which either offers directly or coordinates all necessary primary care, serving as a reliable point of reference for families in maintaining health and coping with health-related problems.

Continuity is, of course, closely related to comprehensiveness, accessibility, and responsiveness. Inaccessibility of a practitioner encourages patients to use emergency rooms or other providers of services, destroying continuity. Referral of patients to others for services that should be within the scope of the primary care unit promotes discontinuous and fragmented care. Failure of a primary care practitioner to seek results from referral sources and to incorporate this information into the patient's record, or failure to accommodate and adapt to the patient's preferences also destroys continuity.

To ensure continuity, primary care units should actively remind and help patients to return for followup visits, attempt to determine reasons for missed appointments or lack of adherence or followup, and maintain unitary and complete patient records which include results of referrals to and consultations with other sources of care.

The patient's record can be an instrument to achieve continuity of care. Historical data, progress notes and information from referrals, laboratories, emergency rooms and other agencies can be maintained in the record. Consideration should be given to a problem-oriented focus. The parents should be familiar with the content of the record and may maintain a summary for family use. If parents transport the record, or a component of it, e.g., emergency room record, from provider to provider, two essential functions are performed: parents are informed, and information is conveyed safely and rapidly.

Appropriate Personnel Arrangements

Primary care units should establish practice patterns involving collaboration among various health professionals which make possible the effective delivery of needed primary care services at reasonable cost. It is increasingly difficult for a single practitioner to master in depth all the fields of knowledge and the full range of skills that bear upon the physical and mental health of the patients they see. Practice patterns should encourage primary care practitioners to work closely with other personnel whose talents and expertise complement their own. Primary care units which are organized to provide for substantial collaboration among various types of health professionals can provide better and more cost-effective care.

Accountability

Primary care units should review regularly both the process and outcomes of care to provide information which is useful in quality improvement. While the Panel recognizes that periodic quality reviews may be an expensive process for some smaller primary care units to set up, we are encouraged by the fact that considerable work is currently under way by professional organizations and others to develop better and simpler methods for internal quality review that will make this a realistic objective for all kinds of provider arrangements in the years ahead. Internal reviews should be designed and conducted to provide information useful in quality improvement undertaken internally by the provider unit, by funding sources, by the State health authority, or by users of care and their representatives.

Consumer Participation

Primary care units should establish a systematic connection with users of care and other categories of consumer representatives to help assure that their services are responsive to the needs of those they serve, and that the program receives broad community support. Most private practitioners believe that their ability to attract and keep patients is the best indication of whether they are responding to the needs of patients and their families. Any more structured involvement of consumers is difficult to achieve in a private practice setting.

In organized care settings, on the other hand, systematic involvement of the users of care and their representatives is both possible and desirable. It is particularly important in those primary care units where there is substantial social or cultural distance between the target population and those who are providing services. Programs successful in reaching a high proportion of their target population with primary care tend in some way to have established significant roots in the community. Such connections take many forms, including partnership arrangements in which responsibility for the program is genuinely shared between providers and users of services, consumer advisory bodies, active collaboration with existing consumer organizations, and training and employment of community residents as paraprofessional employees of the health program.

Consumers of health care can contribute much to how programs they use should be designed and should operate. The needs, wants, and judgments of consumers must be considered very carefully in designing and operating health programs.

Consumers serving on advisory or governing committees and boards for Community Health Centers, Health Service Agencies, health departments, or hospitals should be provided a comprehensive orientation in existing services and health delivery systems in the community, including the interrelationship among various institutions and programs; and in how standards are set, how new services are developed, how audits are conducted, and how budgets are prepared.

Adequate funds should be allocated for training interested and involved consumer representatives so they may be effective participants on boards, committees, and councils. Governing bodies and advisory councils may also include other consumer representatives with special expertise in community affairs, local government, finance and banking, legal affairs, trade unions, voluntary health agencies, and public and private social service agencies. Such individuals can be extremely helpful in creating programmatic links with other parts of the community, and in making clear to the broader community its stake in the health program.

Partnership with Parents

An awareness of the central role of the family in all aspects of maintaining child health must permeate the activities and organization of primary care units. Health professionals have many opportunities to support families in their efforts to rear strong, healthy, and resilient children.

Both individual providers and organized health programs and institutions can respond to family needs in ways that support or undermine family functioning and a sense of parental competence, and that encourage or discourage parental efforts to become effective collaborators with health professionals in assessing and maintaining their children's health, as well as caring for them when they are ill.

Since parents are the ultimate source of ongoing care and responsibility for their children, it is essential that they be treated with the respect and sensitivity which will enhance and support their key role. Time, a proper setting, caring to ask and the skills to listen, must be integral parts of health services. Most studies support the conclusion that:

> The parents . . . know their child far better than those trying to help care for him. Listening to parents, carefully noting their observations, putting them at ease, and hearing out their worries even if they appear unrelated can help to provide them with the emotional resources needed to help their child. Impatience or misunderstanding with parents can impede their inclusion in the therapeutic process, particularly because parents will continue to have caring responsibility for the child after his illness—a point easily overlooked during the time of acute intervention (7).

The Panel believes that all providers of primary care to children and pregnant women should seek to incorporate most of these attributes into their delivery arrangements, and that families whose children have special needs for a broad range of health and related services may find it preferable to obtain their care from a primary care unit which has incorporated most or all of these characteristics. Not all providers will be able to, or will wish to, incorporate these attributes to the same degree. Their salience, in our judgment, varies directly with the proportion of the target population which is at high socioeconomic or health risk, and with the scope of health needs with which the particular provider is called upon to deal.

Public officials, administrators, and health planners should all become aware of these attributes, so that they may support policies which will help providers to incorporate them. There should be special efforts to make parents and other consumers aware of these attributes, to assist them in judging what kind of primary care settings are most likely to meet their needs. Purchasers of health insurance, including management and labor, should take cognizance of these attributes and the influence of third-party payments in supporting desirable provider arrangements.

STRENGTHENING EXISTING PROVIDER ARRANGEMENTS

In varying degrees, existing primary care arrangements already have many of the attributes the Panel has identified as important. We discuss below some of the specific steps that should be taken so that, over the coming decade, more of these characteristics can be incorporated in individual and small group office-based practices, hospital outpatient departments, comprehensive health centers, HMO's, health department clinics, and school and pre-school health services.

Individual Practitioners and Small Group Practices

A very high proportion of children's health care and prenatal care—approximately 76 percent of all child health visits and 81 percent of all prenatal visits (*8, 9*)—is provided by pediatricians, obstetricians, and family and general practitioners in individual practice or small group practice. Pediatricians and obstetricians in private office-based practice tend to cluster in more urban and more affluent areas than family practitioners, who are more likely to live in small towns or rural areas (*1*).

The solo practitioner usually works with a small office staff; group practice usually consists of three or more physicians formally joined together to provide medical care. This latter form of practice has been growing among pediatricians over the past two decades, and will probably continue to do so. (See chapter 12.)

Large numbers of families and individuals have found this mode of practice offers the most personalized, complete, continuous, and satisfactory way of obtaining medical care. The Panel believes that, although individual and small group practice have been enormously successful over the years, these forms of practice can be considerably strengthened in two major respects. They can become more effective in their efforts to help families to prevent disease and promote and maintain health, and they can be equipped to become a better gateway to a broad range of services which their patients may need, but which they cannot offer directly. It would be a great advantage to them and their patients if they could more readily mobilize the help of others including social workers, psychologists, speech and hearing therapists, physical and occupational therapists, visiting nurses, and mental health centers.

We believe that the broad spectrum of health needs of children and pregnant women, and the attributes of delivery arrangements most likely to meet these needs, implies that for the future, groups of health professionals, especially when nurse practitioners and other health personnel are included, are preferable to physicians working alone, and that public policy should be designed to promote a closer relationship between office-based practitioners and other sources of care and service. Currently, referral and consulation patterns of private practitioners tend to include medical specialists, but not other health and health-related professionals.

The Panel recommends that, over the long term, individual primary care physicians be encouraged to join in practice with other physicians and with other health professionals. Dentists, too, should be encouraged to join with other dental professionals in practice. Simultaneously, better links must be developed between physicians and dentists in office-based practice, and other sources of care, services, and support in the community.

The Panel has been particularly impressed with the unexplored potential of the last objective to achieve great gains in child health. Some of the attributes of the primary care unit which we have described are difficult for an individual practitioner or small office-based group to incorporate directly, but linkages can be forged which will provide a capacity for outreach, coordination and accountability. For example, the local public health agency may provide the local physicians with a part-time public health nurse or social worker; some health departments provide office space in exchange for the physician's participation in the department's health service programs. Many visiting nurse agencies have close and active working relationships with physicians in private practice. In some rural areas, the agricultural extension agent has been enlisted to provide followup services, and some welfare departments work closely and effectively with private practitioners to make sure that referrals are completed and to help coordinate care. Services such as food supplements and nutrition education, crisis counseling, classes in preparation for childbirth or parenting, alcohol and drug abuse programs are often offered by health departments, health centers, and hospitals, and needed by some of the patients of private practitioners. If there were better linkages between these programs and institutions and the private practitioner, the latter's capacity to deal with a broad range of problems would be greatly enhanced. *Therefore, both public and private funds should be made available for demonstrations of better ways of making health-related services accessible to physicians and dentists in office-based practice, and of encouraging them to make use of such services.*

Hospital Outpatient Departments

Hospital outpatient departments are of great significance for the health of children and pregnant women for two main reasons: hospital clinics are the source of ambulatory health services for many mothers and children, and they are typically the setting in which physicians receive most of their training in ambulatory care.

Nationally, about 14 percent of all child health visits are to hospital clinics or emergency rooms; among low-income children over one-fourth of all ambulatory care is rendered through the hospital outpatient department or emergency room (*6*).

Many families use hospitals as their regular source of care. In some areas of American cities there are no other options, particularly for pediatric care. For many families there are no other options they can afford—most hospitals accept Medicaid patients, and many hospitals accept patients who have no source of payment. But often, hospitals are chosen as the preferred provider. Some families form an abiding attachment to the place where their child was born, and continue to return there for care. For others, the decision to use the hospital outpatient department (OPD) or emergency room (ER) may be based on the quality of medical personnel as compared to those in other health care settings, their perception of the severity of a child's illness, hours at which care can be sought or is required, and the expense and inconvenience they are likely to incur in seeking care elsewhere.

Many hospital outpatient departments offer extremely high quality ambulatory pediatric and prenatal services. However, care in this setting is often episodic, and—with some notable exceptions—frequently marked by anonymity, fragmentation, crisis orientation, discontinuity and high cost.

These defects, which undermine the effectiveness of much hospital-based ambulatory care for the patient, also diminish the quality of training received by pediatricians, obstetricians, family practitioners and nurse practitioners, for it is in the hospital outpatient setting that most of these practitioners, and other health-related professionals such as social workers, receive the bulk of their training in ambulatory care. Many current problems are thus perpetuated.

There are many obstacles that keep hospitals from providing more accessible, continuing and comprehensive ambulatory care to children and pregnant women. In some areas, physicians in private practice who are on the hospital's attending staff may view high quality hospital-based primary care programs as a competitive threat. But the most formidable problems are those that stem from cost considerations and prevailing arrangements for financing hospital outpatient care:

- Costs of providing services in a hospital setting are high. Costs of space, utilities, maintenance of medical records, etc., are substantially greater in a hospital than in a doctor's office. Some experts estimate these factors cause a typical office visit in a hospital to cost $20 more than in a nonhospital setting.
- The vast majority of organized ambulatory care provided in hospitals is performed in teaching hospitals where costs are especially high because of the added costs of training. Although private foundations and Federal and State Governments have made grants to some hospitals to offset training costs in primary

care, many hospitals do not receive such subsidies; even many that do find them too limited.

- The cost differential for visits to an OPD is exacerbated by the way hospitals distribute costs. The costs (but not the revenues) are distributed disproportionately to the OPD, in part because the biggest single payer for hospital care, Medicare, requires an averaging approach, whereby most hospitals choose to attribute total costs to various parts of the hospital based on such factors as how much space the program occupies. And although most clinic spaces are utilized only 8 hours a day, allocation of their costs for housekeeping and maintenance are based upon 24-hour-a-day utilization.
- While present arrangements make costs high, funds to cover these costs are especially limited. Primary care providers are at fee disadvantage compared to specialists, who are more apt to recoup money by performing procedures which are covered and adequately reimbursed by insurers. Also, much less of the primary care providers' overhead, staff, and similar expenses can be borne by other hospital sources. Medicaid's fixed fees for outpatient clinic visits are typically lower than the "usual, reasonable, and customary charges," and even though this same fee may be paid to out-of-hospital providers, it is more burdensome to the hospital-based provider whose costs are higher. In the case of private insurance, outpatient care is frequently not covered.
- Public hospitals frequently have especially severe problems. In areas with relatively generous Medicaid benefits and a large number of hospitals, there may actually be competition for Medicaid-eligible patients, as some private voluntary hospitals "skim" off Medicaid-eligible patients, leaving other community hospitals and the public hospitals to care for the medically indigent and illegal immigrants.

To provide children and pregnant women with ambulatory services characterized by continuity, comprehensiveness, and accessibility—resulting in not only better and more cost-effective care, but also significantly improved professional training—hospitals which provide a substantial amount of outpatient care to children and pregnant women must make fundamental changes in their organizational arrangements.

Many hospitals have already succeeded in making the kinds of changes we view as necessary. These include the following:

- *Hospitals should establish primary care centers of various kinds with the help of both public and private funds.* These primary care centers can incorporate many functions previously performed in specialized clinics but with a special emphasis on making services accessible, comprehensive, continuing, and responsive to the needs of the families served. Especially when there is a stable source of funding, this can be done by utilizing staff physicians, nurse practitioners, and other health related personnel, and establishing strong links to the community. In some hospital OPD's continuity of care has been promoted by using a team approach in which regular faculty remain with a group of patients and only the trainees change. Also, residents and families or patients can be matched up and stay together for the full course of the resident's training in order to provide continuity to both patient and trainee.

- *Further development of hospital-based group practice should also be encouraged* because greater continuity and more personal care is possible in these settings than in traditional OPD's. However, most hospital-based group practice arrangements tend to offer a narrower range of services than the hospital-based primary care centers, and often find it more difficult to provide the full range of health-related services which are so important to children with special needs, or who are at high risk for either social or medical reasons.
- Depending upon circumstances, *some hospitals should assume responsibility for the creation and operation of decentralized primary care units in nearby or outlying neighborhoods,* with appropriate incentives for their use. In many areas hospitals provide the best organizational locus for one or more peripheral neighborhood primary care centers, which may be needed to provide the target population with services that are both geographically and psychologically accessible.
- *Hospital outpatient departments when they are not the regular source of care, and hospital emergency rooms, should assure systematic transmittal of medical information to the patient's primary care provider, and establish mechanisms for encouraging patients and their families without a regular source of primary care to select and use one.*
- *Linkages between hospital OPD's and community services must be improved to enable both to function more effectively.* First, hospital OPD's must be more available to community primary care providers for consultation and specialized service backup. All medical schools, schools of nursing and teaching hospitals with pediatric, family medicine, and obstetric departments, including those on which large numbers of families do *not* depend for their primary ambulatory care, should be encouraged to establish more effective working relationships with private practitioners, free-standing child and community health centers, public health clinics, school health programs, day care centers, and correctional and other residential institutions. They should offer to all of these other sources of care the kinds of collaboration and backup services they most need, including medical consultation, secondary and tertiary care, and various psychosocial services. In addition, hospital primary care units and group practices should be able to mobilize the services of other agencies, including home health agencies, community mental health centers, public health departments, family planning centers and social agencies on behalf of the families they serve.
- To provide an optimal training setting, *the hospital OPD must be organized in such a way that health professionals of all kinds, and at all stages of their training, can learn to provide continuing,*

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personalized care, and to collaborate with parents and with other health professionals, including other physicians, nurses, social workers, psychologists, nutritionists, and educators. Especially, there must be opportunities to acquire skills in caring for children with developmental disabilities, chronic illness, and handicapping conditions, as well as skills in counseling, anticipatory guidance, developmental appraisal, coordination of services, planning comprehensive care, and mobilizing available community resources (*10*).

It is extremely difficult for hospital OPD's to change in the ways we recommend unless changes are made in financing arrangements of third party payers, grant programs, and hospitals themselves. Most recent modifications of OPD's have been made using private or Federal demonstration grants. If more hospitals are to provide more effective ambulatory services to children and pregnant women, and do so over the long run, the following steps must be taken:

- *The costs of teaching in ambulatory settings must be financed through subsidies for this purpose, or by increased payments from third party payers.* These costs include the reduced productivity of health professionals engaged in teaching, and the support of special services and personnel that can demonstrate and teach the skills required to assess patient needs and to counsel patients without excessive utilization of technological procedures.
- *New methods of paying for primary care rendered by hospitals should be developed, using public and private demonstration funds.* Among payment mechanisms which should be considered are capitation payments to primary care units which are not full HMO's; methods whereby savings which accrue from reduced use of inpatient care as a result of more effective outpatient care can be identified and treated in ways that provide incentives toward making ambulatory care more accessible and more appropriate.
- *Grants under Section 328 of the Public Health Service Act should be expanded to support more comprehensive care centers in hospital settings.*
- *The management and efficiency of hospital-based ambulatory care must be improved,* possibly through establishment of separate cost centers which would make the various components of the program more accountable. Further studies and demonstrations are needed to define more clearly how separate cost centers and similar mechanisms might be employed to provide ambulatory health care more efficiently under hospital auspices.
- *Methods of defining and allocating costs within hospitals must be modified.* This could probably be brought about most expeditiously through changing the Medicare rules which result in attribution of unreasonable amounts of expenses to outpatient clinics.
- Other financing changes recommended elsewhere in this report (see chapter 9) will make it easier to implement our proposed modifications in hospital OPD's. These changes include raising payment levels for primary care, expanding third-party coverage, and providing a higher priority for outpatient care. In addition, as

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recommended in chapter 8, special provisions must be made to reimburse hospitals for care to the poor with no sources of third-party payments, including refugees and illegal immigrants.

Publicly Financed Comprehensive Care Centers

Publicly financed or subsidized comprehensive care settings include Community Health Centers (CHC's), Migrant Health Centers, Children and Youth projects (C&Y), Maternity and Infant Care projects (MIC), some health department programs, and rural primary care centers. These programs are intended to provide a full range of primary health care services, are linked to secondary and tertiary care, and usually also provide social services and some support services. They employ physicians, certified nurse midwives, and nurse practitioners, and most do so very effectively. Sometimes they provide environmental interventions, and many have a commitment to community participation, outreach, and other mechanisms for minimizing access barriers.

Many of these programs have been highly effective in providing previously unreached populations with needed health services, with subsequent decreases in hospitalization rates, infant mortality rates, and the incidence of preventable diseases in the areas served. In addition, while not all programs have been of equally high quality and cost effectiveness, there is ample evidence that quality and cost compare very favorably with those of other provider arrangements, many of which offer a far narrower range of services. To cite but three examples:

- A recent study showed that in one community total Medicaid payments, including hospitalization, were as much as 60 percent more for persons not getting their care from community health centers than for users of CHC's. Cost differences in other communities were smaller but still significant (*11*).
- Within 2 years after a neighborhood health center was established in a Rochester location which had previously been the site of a clinic with limited services, there was a 38-percent decrease in emergency room visits by center area children. During the same period, pediatric visits to the emergency room from other areas increased by 29 percent (*12*).
- A new study comparing outcomes for pregnant women in a maternity and infant care project in Cleveland with those of a similar group of women getting care at the same hospital, but without the supplementary services (which included more patient education, nutrition counseling, social service assessment and intervention, special services for adolescents, and missed appointment followup), shows women receiving care through the maternity and infant care project experienced 60 percent less perinatal mortality (*13*).

Despite their positive track record, comprehensive care centers still serve only a fraction of eligible children and parents in the United States—about 4 million children in fiscal year 1981—although we believe they should serve far more. They remain a model for service delivery with great unfilled potential to deliver high-quality care in the Nation's areas of provider scarcity and high health needs.

There are two major types of federally supported comprehensive care centers.

Community and Migrant Health Centers

Community Health Centers were first funded by the Office of Economic Opportunity in 1966. A similar Public Health Service (PHS) program was started in 1968, and in 1973 all program authority was given to the PHS. Roughly 150 early centers were characterized by project grants to community groups with consumer governing boards, employment of community residents, fairly large size, significant capital investment, and provision of a full range of preventive and support services as well as basic medical intervention.

Two variations from the original model occurred during the mid-1970's. First, new centers known as Urban and Rural Health Initiatives were restricted to a more narrow medical approach to care, and health-related services were reduced in existing centers. Program administrators and beneficiaries criticized the narrower range of services and were successful in obtaining a 1978 legislative requirement that funding for most of the services be restored. Second, new centers tended to be smaller and less capital-intensive, a modification received positively insofar as it increased flexibility to meet needs of small communities.

Between 1977 and 1981, funding increased more than 60 percent and capacity doubled. In fiscal year 1981 roughly 1,000 Community and Migrant Health Centers will serve a total of nearly 6 million persons—3 million children—at a grant cost of $398 million. Nearly all current efforts are in high poverty underserved areas.

Centers are still funded through project grants and nearly all have consumer boards. The centers are required to provide most primary health care, transportation and some support services. Home health, dental, bilingual and outreach services and health-nutrition education must be provided on demonstration of need; environmental and psychosocial services are optional and often supported by other grants.

Maternity and Infant Care and Children and Youth Projects

The Federal Government also funds primary care projects for children and pregnant women indirectly, through a program of Maternal and Child Health (MCH) formula grants to States. These programs were originally funded through direct project grants by the HEW Children's Bureau under Title V. Children and Youth Projects (C&Y) provided children with medical, nursing, nutrition, social work, and a broad range of support services. Maternity and Infant Care (MIC) project grants, begun in 1963, focused on high-risk pregnant women and infants, including their needs for primary care and related services. Both types often had consumer advisory, but not consumer governing boards.

Starting in 1974, funds for C&Y and MIC projects were folded into the State formula grants of the maternal and child health program. States were required at least to maintain pre-1974 levels of service, States without at least one MIC and C&Y project were required to start one, and it was hoped that they would further replicate these projects in areas that still lacked access to care.

While some States expanded their support of these programs, most States chose to continue their other maternal and child health activities rather than expand projects which some regarded as federally imposed, which were expensive when compared to less comprehensive and more traditional public health services targeted on similar groups, and which required greater adherence to Federal standards. In fiscal year 1981, 88 MIC projects with $62 million in Federal grant funds will serve about 450,000 mothers and 300,000 infants. Ninety-six C&Y projects will serve about 600,000 individuals with $65 million in grant funds.

Manpower Support

An integral part of Federal support for primary care in underserved areas is the National Health Service Corps (NHSC), which deploys health professionals in underserved areas, with or without a prior scholarship obligation. When the Corps was initiated in fiscal year 1971, most physicians were placed in a solo practice setting, many in areas with the potential for self-sufficiency. This occasionally led to conflict with physicians in private practice and often left high poverty areas unserved. The current emphasis is on placing such personnel into comprehensive care units, to better meet the multiple problems of high poverty areas. However, public health departments and public hospitals are currently not eligible for a NHSC placement unless they reimburse the Federal Government for the cost of that individual's salary.

In 1981 the NHSC will deploy 2,500 primary care practitioners at a total field cost of $87 million. About 65 percent will be placed in Community and Migrant Health Centers. The remainder will serve in 270 independent practice sites which comprise a slightly different model of health care delivery. Health-related preventive, support and psychosocial services are not as likely to be provided, and most independent sites are located outside of high poverty underserved areas.

Strategies for Improvement

The principal limitation on all of these comprehensive care centers has been their high dependence on fluctuating and unpredictable funding. Various efforts have been made to reduce this dependence on Federal grant support, including broadening eligibility to include the non-poor with sliding fee arrangements, offering care to those outside original catchment areas, attempting to enlarge the component of care reimbursable by Medicaid, searching for other public grant monies, and conversion to an HMO practice model. These efforts have resulted in significant diversification of funding for most centers, although core support from Federal grants remains an essential budget component for most. (Some comprehensive care centers, including some neighborhood clinics operated jointly by hospitals and local health departments, are funded exclusively by States and counties.)

Fiscal pressures have resulted in many centers curtailing services for which third-party reimbursement was not readily available, even when these services were considered particularly important and effective. Recent data suggest, for example, that among those centers with increasing financial problems, outreach and preventive services tend to receive decreased emphasis (*14*).

Another problem surrounding these programs has been the development of an appropriate relationship between the comprehensive health centers and the process of State and local planning, resource allocation and standard setting for maternal and child health care. Historically the centers have relied on a direct relationship with Federal authorities for their initiation and continuing support, substantially bypassing State and local government. This was logical at the outset because the centers were created in large measure to meet needs which State authorities had consistently failed to address. There remains an understandable anxiety among the directors of many centers that State involvement or control might undermine their effective operation and inhibit the development of additional centers. But all would agree that lack of coordination in selecting sites and relating to parallel efforts under State and local sponsorship has at times led to inefficiencies in the use of scarce primary care resources. (Our recommendations for resolving this dilemma appear in chapter 10.)

The design of most federally supported comprehensive care arrangements is highly consistent with the primary care units the Panel supports; they are likely to have the characteristics we have identified as effective. In some areas they continue to be the only viable mechanism for delivering cost-effective care of high quality to poor mothers and children. *The Panel strongly recommends that Federal and State Governments continue to regard comprehensive care programs such as the Community and Migrant Health Centers, Maternal and Infant Care Centers, and Children and Youth Centers—together with deployment of National Health Service Corps personnel—as the best instruments for increasing access to and availability of appropriate primary care services for children and pregnant women in underserved areas.* This means that:

- The Congress should increase its grant support, on as predictable a basis as possible, to allow existing comprehensive care centers to serve more clients and to permit the addition of comprehensive care centers to new sites as needed;
- The States should similarly seek to support and expand MIC and C&Y projects. When the degree of support which MIC and C&Y centers receive under existing arrangements is not commensurate with their potential for improving maternal and child health in underserved areas, Federal authorities should take the initiative to stimulate their expansion and continued successful operation;
- The Department of Health and Human Services should further develop and facilitate support of comprehensive care centers by providing technical assistance, revising regulations, and requesting legislative changes if necessary, to make it easier for the centers to

draw on and coordinate with various other sources of Federal and State funds, including Medicaid, family planning, preventive health services, Head Start, Title XX, and mental health services. Also, in some communities MIC and C&Y projects might best be colocated, or provided at the same site as a Community Health Center;

- Federal support for the development of nurse practitioner and nurse midwife clinics in sparsely populated areas should be increased.

Health Maintenance Organizations (HMO's)

At present, approximately 5 percent of the Nation's children and pregnant women are cared for by HMO's (prepaid group practices and independent practice associations). Since HMO enrollment is primarily through employed groups, families who belong to them are predominantly middle and upper middle class, although a few urban HMO's have a significant lower income clientele. HMO's, which originally were a West and East Coast phenomenon, are now developing throughout the United States. In 1971, there were 39 plans serving 3.5 million people (*15*). By June, 1980 there were 234 serving an estimated 9.03 million persons (*16*). In another 10 years HMO's are expected to serve 20 million Americans.

HMO's have the potential to do a more effective job than they now do in serving women in the reproductive age group, and children. They provide cost and quality controls and the opportunity for collaboration among a variety of health workers, a combination that is difficult to find outside of organized settings. Financing is not generally pegged to the specific services provided, allowing greater latitude for the provision of a broad array of appropriate services by a variety of personnel. Financial incentives operate, at least in principle, to encourage the provision of preventive services, primary care and health education and to reduce unnecessary care. For example, the Puget Sound HMO estimated that by integrating a stepped-up prevention program focused on high risk children into its comprehensive care program, it was able to significantly reduce the need for other services, with resulting savings of $100,000 per year (*17*).

The two best safeguards that consumers have to protect them from possible underutilization of services from HMO's are the potential of the HMO to undertake (1) rigorous quality reviews, since there is an enrolled population and relatively easy access to comprehensive records, and (2) a systematic program to keep consumers well informed so they can monitor their own and their children's care.

Of particular importance to children and their parents is the fact that the HMO places no limits on primary care visits, that psychosocial services and counseling are offered in many HMO's through health education classes and health promotion activities, and that most HMO's systematically and actively encourage well-child examinations and promote immunizations.

The Panel urges that all HMO's review and expand their ability to provide all needed services to children and pregnant women as part of their regular benefit package. Federal policies toward HMO's should promote such activities.

Financial pressures and policies governing eligibility operate to inhibit enrollment of low-income populations in HMO's. Current Federal efforts to develop HMO's as a means of constraining health costs and to pressure HMO's to operate without government subsidies have had the indirect effect of discouraging them from attempting to serve larger numbers of the poor. The fluctuating eligibility status of many poor families for third party reimbursement adds another complication for a program which puts high priority on continuity of care, and where projected savings may be associated with long term membership. Categorical funding aimed at specific target populations and at provision of certain types of care (i.e., outpatient care but not inpatient care) is at variance with what the HMO does best, providing all family members with comprehensive coverage for all health services. At present, only about 1 percent of Medicaid beneficiaries are enrolled in HMO's.

The Panel recognizes that for the near future in most areas of the country, HMO's will not be the dominant mode of service delivery. But the promise of this service delivery mode at its best is substantial. *Federal authorities should take three steps to make it more attractive for HMO's to enroll low-income mothers and children:*

- *Grant funds should be provided as an incentive or partial subsidy for those HMO's enrolling substantial numbers of low-income children and parents.*
- *Medicaid regulations regarding scope of benefits should be waived, as necessary, to enable HMO's enrolling low-income families to offer the same benefit package to these families as to other subscribers.*
- *Further efforts should be made to develop realistic models of prospective reimbursement to HMO's for the care of groups of low-income children and families.*

Where prepaid systems for providing cost effective comprehensive care to mothers and children are already in operation, such systems should be encouraged to add low-income families. The use of grant funds and the waiver of certain Medicaid regulations (as permitted under existing law) would make possible Federal subsidy for low-income persons who may need certain additional services to help them make optimal use of the HMO, and would encourage the use of prepaid capitation payments for both inpatient and outpatient care. For low-income children and families enrolled in HMO's it should be required that if a family leaves the Medicaid rolls, the State Medicaid program reports such loss of eligibility promptly and extends HMO eligibility for at least 6 months to ensure continuity of care.

HMO-Medicaid demonstrations, which would waive State restrictions on care and develop reporting requirements germane to the HMO type of operation, are an important form of health care experiment. Such programs should allow low-income children and their parents to receive the same benefit package and be cared for in the same way as other HMO clients; participant families should receive the assurance that no benefits available to other Medicaid families will be denied to them (e.g., dental benefits). Where HMO's have developed particularly valuable maternal and child health programs (i.e., preventive services, health promotion, psychosocial and educational counseling) such programs should be studied as demonstrations of what might be encouraged in other HMO's with similar populations and settings. Federal effort should concentrate not only on extending access but on generalizing successful elements of some HMO's to other HMO's.

Health Department Clinics

It is estimated that roughly 2,000 State, county and city health departments in the United States are involved in the delivery of direct health services to mothers and children. Most do not offer comprehensive care, but rather pre- and postnatal care, well-child care, immunization services, school health exams, and other primary preventive services. During the 1960's and 1970's, however, some large health departments began to assume responsibility for establishing and operating comprehensive health centers. A significant number of such centers are now in operation, serving approximately 0.5 million children. A recent survey indicates that over half the local health departments in cities with more than 100,000 population now sponsor at least one facility offering pediatric primary health care. Approximately one-quarter of these departments operate more than five such facilities (*18*).

Important regional differences prevail, with health departments in the Southeast, Pacific, and Mountain areas more involved in medical care delivery than those elsewhere. Funds from Title V, Section 330 of the Public Health Service Act, and more recently EPSDT, have provided considerable Federal support for preventive care in health department clinics. The widespread existence of health department facilities and personnel has made them a natural base in the eyes of many for further development of maternal and child health services, even though both their budgets and their services usually are quite limited at present. In underserved areas, the health department may be the most realistic institutional base for further development of primary care services.

Trend data suggest that maternal and child use of public health clinics has increased over the past decade in response to the expanded availability of funds for services, in large measure because of the EPSDT program. Twenty-three States rely exclusively on health department clinics to carry out the screening portion of EPSDT; only eight States implement EPSDT without any participation of health department clinics. Nationwide, one in five new mothers in 1976 received some maternity nursing services from health department personnel, and more than 17 percent of all infants received care in health department well-child clinics. Comparable use rates have been experienced in health department family planning clinics. Thus health department clinics remain a significant component of the maternal and child health care delivery system, and have grown in their relative importance over the past 20 years (*18, 19*).

Health department funding sources vary. City or county funds are the most common source of support, along with limited assistance from State and Federal Title V, and Title XIX and Public Health Service (Section 314(d)) monies. The larger rural health departments found mostly in the Southeast are heavily State supported while urban health departments, especially in New England, rely primarily on local support (*19*). Those providing comprehensive care are usually either direct recipients of Federal primary care funds (e.g., Denver, Cincinnati) or have created networks including Federal programs and those funded from their own sources (e.g., Boston). Many rural health departments offer somewhat less comprehensive primary care to a large, sparsely populated area, sometimes through satellite or mobile clinics.

Health departments also vary in strength and effectiveness. In several States, the State health department is characterized by strong leadership and strong support from the State legislature. In Michigan and several other States, the health department's maternal and child health unit controls the EPSDT, Title V, and WIC accounts, enabling the same people who administer the programs to make decisions about the use of monies in these programs. The department also gets a prospective EPSDT budget from the State legislature, based on anticipated Medicaid reimbursements for the year. EPSDT money therefore can be used in a purchase-of-services mode, much like a formula grant.

In Alabama, the health department received a modest increase in its maternal and child health funding over the last 3 years, and has upgraded and extended its maternal and child health services. During this same period, the statewide infant mortality rate fell from 20.0 to 14.3 per 1,000 live births, while the racial differences in infant mortality declined by 75 percent (*20*).

In Georgia all maternal and child health services are located in one section of the State health department. In addition, there is a yearly appropriation of approximately $8,830,000 in State monies to fund the high risk prenatal care and other maternal and child health programs. Because of this coordinated effort, Georgia has made significant strides in the development of a regionalized system of perinatal care. In addition, immunization levels currently exceed 90 percent, and the Supplemental Food Program for Women, Infants and Children (WIC) has enrolled 62,000 mothers, infants and children in all counties of the State. All 159 counties offer child care through the local health department, and all but 15 also provide prenatal care. A network of genetic services has been devised with Federal and State funds through a partnership between medical and nursing schools, education, health departments, and private practitioners (*21*).

In cities such as Denver and Cincinnati, local health agencies have been able to utilize a combination of Federal, State and local funds to create a network of comprehensive care services with dramatic impact on the health status of children and pregnant women.

Weaker State and local health departments have not been similarly successful in pulling together programs and funds. The General Accounting Office found, for example, that State maternal and child health agencies "have generally not fulfilled the role of focal point for improved management of activities directed at improving pregnancy outcome" (*22*). The main problems are limitations in the nature of the programs, in administrative capacity, and in funds.

A further complicating factor is that in some areas of the country, services have not been responsive to the needs of racial minorities. Likewise, in some communities health departments are dominated by the State or local medical society, which may oppose their assuming an expanded role in the provision of a full range of primary care services. It should be noted, however, that many health departments have successfully overcome these adversities.

A central strategic issue is whether to recommend that the promising developments of the recent past be reinforced and health departments made the base for the further establishment of comprehensive primary care units, or whether to place policy emphasis on other sponsors and sites of care.

It can be argued that because the health department's historic role has been to provide environmental and preventive health services, without any clear mandate to provide comprehensive primary care services, it is inappropriate to add new primary care services to existing health department clinics. This line of reasoning emphasizes the fragmentary nature of traditional health department preventive care clinics, their limited availability (e.g., services are often provided in only a few sites, sometimes on only 1 day or for a few hours each week), and the difficulty many health departments have in attracting qualified personnel. On the other hand, health departments represent the only substantial existing infrastructure on which to base care in many low-income areas (almost 10 percent of departments report being the only source of organized ambulatory care in their district), comprehensive services sponsored by health departments have been delivered in some places during the past decade, and more health departments could be effective sources of comprehensive care in many low-income areas if strengthened and given the needed resources.

Without additional public support, many State and local health departments will continue to have a limited capacity to provide primary health care services. It also seems clear that because some Federal initiatives have in effect circumvented State health departments by directly funding local grantees, these departments are somewhat demoralized and in need of a clear definition of their appropriate role in the provision of primary care services. Health department emphasis on primary care to mothers and children has in many areas been eroded by demographic shifts requiring added attention to the needs of the elderly, and by the greater availability of funds for services to the elderly, especially through Medicare.

The Panel recognizes that health departments have certain unique functions and responsibilities. (See chapter 10.) With regard to their role in the delivery of primary care services, the Panel concludes that as with other delivery arrangements, no single policy will suffice for all States and localities. In some areas, health departments will indeed offer the best opportunities for making health services more accessible and available. In those areas they should be fully utilized.

The Panel believes that in general, support for primary care units organized and sponsored by qualified local and State health departments will be more important during the next decade than in the past, especially in central cities and rural areas. The need for comprehensive health services from health departments can only increase in a period of relative economic hardship. In many areas, no other provider is as likely to offer care at moderate expense to the inner city poor, the medically indigent, and additional populations who would otherwise seek care from hospitals, often at considerably higher public costs.

We therefore recommend that priority be given by Federal, State and local authorities to support of health department efforts to offer comprehensive primary care, rather than individual components of preventive care. We also encourage State health departments and/or Title V agencies to assist in identifying areas where comprehensive care centers under health department sponsorship would be desirable, and to foster the development of such settings to replace or extend more limited health department clinics.

Federal support of health department-sponsored comprehensive care to children and pregnant women should be contingent on competence to conduct such programs, and adequate provisions for consumer involvement in service planning. We believe that a major mechanism to assure the adequacy of health department efforts in primary care is the establishment of new and specific national standards for health department maternal and child health programs and clinics. Efforts to establish such standards were initiated under the auspices of the Department of Health and Human Services, but lapsed for the lack of funding. We believe the standard-setting process deserves new impetus in the immediate future. The standards should be broadly disseminated and should provide the basis for Federal and State determinations about funding of future health department programs.

We also believe that it is imperative that more bridges be built between public health agencies and medical centers. New relationships must be developed whereby health departments, medical and nursing schools and teaching hospitals can work much more closely together. In some instances, they may be able to consult with each other, and even monitor each other's performance to the benefit of all institutions involved. Both public and private funds should be made available to explore and demonstrate better ways to remove some of the artificial barriers that separate the worlds of "maternal and child health" in the public health sector from the world of pediatrics, obstetrics, and family practice in the medical education sector.

School Health Services

In promoting wide access to comprehensive primary care for all children, the role of school-based health programs is potentially of major significance. The nation has 16,000 public school districts, and at any one time approximately 99 percent of 6- to 15-year-olds and about 90 percent of 16- and 17-year-olds are enrolled in the schools (*23*). One billion dollars are spent annually, principally from local and State tax revenues, to support a variety of functions categorized as "school health." This is not much in terms of total school expenditures or total health expenditures, but it is a large amount when compared to other public support for child health services. There is a similarly significant commitment of health personnel to school health functions: there are some 30,000 full-time school nurses and almost one of every six pediatricians in the country has accepted some form of responsibility for school health services (*24*).

The traditional role of school health programs has been limited by State law and by custom to a rather narrow range of preventive and educational services. Typically, school-based health personnel have performed routine services such as checking immunization records, advising on the management of children who get sick or injured at school, performing physical examinations for members of athletic teams, and assuring a healthy and safe school environment. Preventive care efforts have varied widely in scope and quality. Because the priorities of school authorities have not always coincided with those of health authorities, school programs have generally been perceived as marginal in their effects on child health. In some instances, valuable preventive care programs, such as dental hygiene programs which once existed in some schools, have diminished in scope or disappeared as a result of reduced tax support, lack of parent advocacy, and insufficient backing from the public health and medical care communities. Such programs have sometimes been perceived by health professionals practicing in the community as competitive with their own services, particularly when they go beyond case finding and referral.

The role of schools in child health is under active debate today. There are those who advocate that schools limit their role to health education, first aid, case finding and referral, and assuring a safe and healthy school environment; others would like them to become sites and/or sponsors for provision of a broad, possibly comprehensive, array of primary care services.

Arguments against expanding the role of schools as providers of comprehensive primary health care include the following:

- In many States the law continues to impose major limitations on such programs.
- Certain problems are inherent in trying to establish priorities of one service sector in the programs and facilities of another. The school superintendent or principal may never accord health services an appropriate priority. In a time of budget cutting, school health services may be the first to go.
- To the extent the school hires health personnel and controls operation of the program, linkages to the public and private health care sectors may prove difficult to create and sustain, further fragmenting services, making quality assurance more difficult, and sometimes creating a dual system of care.
- The schools are closed in the evening, on weekends, and in the summer, ruling out some elements of service continuity.

- Schools usually do not assume responsibility for children until they are 5, which is later than desirable for many forms of preventive intervention, including immunizations and developmental assessment.
- School-based services tend not to reach dropouts and other school-age children who are not in school and may be in greatest need of health services.
- In communities where parents distrust the schools, school-based health services carry the potential for undermining the role of parents as primary care givers.
- Many of the health-related problems of adolescents involve sensitive issues of confidentiality and consent which may be difficult to handle in some schools.

Arguments which support the more active role of schools in the provision of primary care include the following:

- A very high percentage of children can be found in schools.
- Increasingly, schools have space to house additional community services.
- The schools embody the tradition of providing certain basic services to all children, creating the possibility of universal access.
- The merging of health services with health education and promotion, as would be possible in schools, may increase the effectiveness of both.
- Psychosocial and learning-related problems, which have assumed increasing prominence in pediatric care, may be best handled in the schools. This is especially true with the advent of P.L. 94–142, the Education for All Handicapped Children Act, which mandates comprehensive evaluation and appropriate education placement for all children with disabilities.
- The Nation has already made a major commitment to school health, which should not be allowed to operate in a fragmented way outside the mainstream of health care.
- The schools have routine contact with parents, leading to economies of outreach.
- Significant numbers of parents work during the day and cannot readily supervise their children's daily health needs without assistance from the schools.

This issue is not destined to be resolved in the abstract, or at the national level, detached from the realities of individual communities. School-based primary care units will prove a wise investment for some communities but not for others. The role of the school in the community, the availability of other health resources, and the nature of the connections which might be forged between school-based health services and other sources of health services and clinical backup must all be taken into account.

The Panel has studied several highly successful school-based primary health care programs, but we still find it difficult to generalize about the precise characteristics of good programs. Exemplary programs such as those in Hartford, Conn.; Cambridge, Mass.; the Posen-Robbins District of Chicago; Galveston, Tex.; Jackson, Miss.; and St. Paul, Minn. are unique products of local realities, individual entrepreneurship, and close cooperation of the medical sector, making it hard to know which elements are replicable in other sites.

Cambridge, Mass. was able to convert its disjointed and isolated child health services into a program of comprehensive care available to all children through schools and neighborhood centers, with pediatric nurse practitioners as primary care providers. The entire effort was funded by reallocating existing funds; emergency room visits alone fell by 44 percent (*17,24*).

The St. Paul, Minn. Maternity and Infant Care Project opened a comprehensive clinic in an inner-city junior-senior high school, providing athletic, job and college physicals, immunization, weight control and contraceptive information, counseling, and referral. Among other measures of effectiveness, the pregnancy rate for the school population fell from 79 per 1,000 to 35 per 1,000 in 3 years (*17*).

All the highly regarded programs we reviewed appear to have certain attributes in common:

- They tend to employ nurse practitioners or other personnel with training beyond the traditional diploma nurse who have wider health education and primary care responsibilities than usually permitted school health nurses and who have adequate pediatric consultation. In areas with a particularly strong and effective health center, health department or hospital, the program tends to be controlled and supported by the health sector, with space and cooperation provided by the schools but without school control.
- They tend to provide a broad array of services.
- They make major, and successful, efforts to work closely with parents, especially of young children.
- In rural areas, they are often supported and controlled jointly by the education and health sectors, with one or more school nurse practitioners and related personnel offering readily available primary care for families of an entire area.
- They tend to be financed either through a special private grant or public categorical grant, or resourceful pooling of various child health-related sources of continuing revenue.

Funding for school health services is a source of major concern. It clearly is not possible to expand even the most cost-effective school-based primary care without a steady source of revenue at least somewhat greater than that supporting most school health programs. Many schools spend less than 1 percent of their budgets on health services. The best school-based primary care units vary in cost from $30 to $150 per child each year, which is highly cost effective from the standpoint of public health care expenditure but far more than most school health programs now spend. Even highly cost-effective programs not offering complete primary care but capitalizing on the economies of scale available in areas such as preventive dental care require more money than most schools are accustomed to paying. Without increased categorical funding or access to third-party reimbursement, innovative school-based primary care is not likely to expand greatly in the future.

Both the Office of Maternal and Child Health and the EPSDT program have initiated important demonstrations in the support of school health programs. Similarly, many school districts are using ESEA-Title I, Migrant Education, Child Development, CETA, and other monies in partial support of school health services.

Whatever the Federal commitment, State and local support will continue to be a major component of school-based programs. State and local authorities should take note of overall public cost savings achieved by exemplary programs such as those in Hartford, Galveston, Cambridge, and Posen-Robbins in Chicago. In general, the most significant component of cost has been the added training of nurses. But over time these costs have been largely offset by efficiencies and reduced need for direct services by part-time physicians. Moreover, as noted in a recent review of innovative programs, "There is no evidence to date that expanded school-based health services will reduce appropriate encounters with pediatricians. But there is a strong likelihood that inappropriate encounters may be reduced" (*24*).

Various cities and States plan to expand greatly the availability of school-based primary care. Such activities are at various stages of implementation in Pennsylvania, Louisiana, New York, Connecticut, Utah, North Dakota, Colorado, and California. The Robert Wood Johnson Foundation is sponsoring major demonstrations in four of these States. These efforts deserve attention as possible prototypes for more general programs.

The Panel believes school-based health services should be considered a desirable way of delivering primary health services to school-age children, and possibly to preschool children, in those communities where it is possible to utilize schools as the *site* for the provision of health services rendered under the auspices of a health department, health center, hospital, or some combination thereof, and where parents support and actively collaborate in fashioning and maintaining such arrangements.

Steps should be taken by all States and by the Federal Government to establish the necessary preconditions and flexibility to make expanded school-based primary care possible where such arrangements seem appropriate. These steps include:

- The adoption of State laws and policies to permit full use of nurse practitioners, dental auxiliaries and other qualified personnel in the schools in offering a wide range of educational, preventive, and primary care services to children
- The further support of demonstrations in Medicaid reimbursement and the pooling of various public sources of support for child health services rendered in selected school settings
- The facilitation of contractual relationships to provide preceptorships, backup relationships, and other forms of linkage between school health services and those provided by medical schools, hospitals, private group practices, CHC's, RHC's and Children and Youth projects

We also urge that particular attention be given to school-based services for adolescents. Where issues of privacy and confidentiality have been successfully resolved, health programs located in junior high schools and high schools have frequently been very effective in making needed health services, including counseling, more accessible to young people. Further demonstrations should be designed using the school as the site of care for delivery of primary services to this age group by health departments, CHC's, group practices, and hospital-based units.

There are many school systems where it will not seem wise to locate a comprehensive primary care program in the schools. *Schools and school systems without such comprehensive primary care programs should utilize professionally qualified nurses to provide health education, counseling, and preventive services, to work with parents to link children with other health services, and provide professional nursing supervision for children with chronic illness or handicapping conditions.*

These nurses should undertake a vigorous linking and followup role pegged to school entry health requirements, and should help to implement P.L. 94-142, serve as liaison to the home, and provide professional nursing supervision for children with chronic illness or handicapping conditions, many more of whom are now in regular schools as a result of P.L. 94-142. School nurses should be trained in physical assessment, have in-depth education in child development, family counseling, anticipatory guidance, and learning problems; be able to deal with common physical problems and refer others; have a basic public health background; be skilled in basic methods of individual and group health education, and have an in-depth orientation to referral sources in the community.

Preschools and Day Care Centers

There has been a rapid increase in the number of children who attend day care or preschool programs for some or all of the day—as many as 1,533,000, or 25.5 percent of children under age 6 receive preschooling or day care in a licensed facility or a Head Start program. This means that early childhood programs now offer a significant base for helping families to ensure that their children receive basic health services. In addition, these programs can do a great deal to promote and protect the health of the children in their care.

It seems a wise investment to assure adequate resources for prevention and health promotion in facilities for preschoolers, where potentially debilitating problems can be found early, and promptly averted or treated. Furthermore, many children in full-time day care are from high-risk families for whom systematic help in obtaining needed health services is critical. Many are with their families only in the evening, when most community health services are unavailable. The children may receive only acute and episodic health care in the pediatric night clinic, or hospital emergency room, if a daytime trip to the clinic or doctor's office means the loss of a day's pay to the parent. Day care centers may thus offer the best opportunity for assisting families in obtaining preventive services such as immunizations, nutritional services, and periodic assessments for their children. Day care centers are also in a position to help families get children to needed followup care and care for acute illness.

We believe a more extensive commitment of resources aimed at improving health services for children in Head Start and other preschool programs is essential. These resources can be used to link families with sources of ongoing care and to provide certain kinds of health supervision directly. In addition, the health and safety conditions in centers and day care homes where young children spend a significant portion of their time must ensure proper care for health emergencies and avoidance of accidents.

Personnel in day care centers and preschool programs should be given the training and support to enable them, in cooperation with parents, to accomplish the following:

- *Ensure that children receive immunizations and comprehensive health assessments at the proper intervals, with appropriate referral and followup, by helping to link families to sources of continuing care and by arranging for the provision of needed services.*
- *Ensure that appropriate standards for safety, nutrition, infection control, and accident prevention are established and adhered to.*

We recommend more systematic orientation than now typically occurs of staff working in preschool and day care programs to the large potential significance of health services in their programs, and inservice training to equip them, in full collaboration with parents, to use the opportunities they have to improve the health of the children they serve. There is an urgent need for continuing education of preschool personnel, to upgrade their knowledge of child development, mental health practices, and the physical needs of children.

The implementation of these recommendations may require the utilization of a qualified health provider on a full- or part-time basis to provide clinical and program consultation. Qualifications for such a provider should include formal preparation in child growth and development and experience in identifying and caring for the unique health needs of young children.

Some preschool programs arrange for continuing health supervision by a trained nonphysician, such as a nurse practitioner, based in a health department, community health center, or hospital which provides the necessary clinical backup. One nurse may cover about five day care centers, spending enough time in each center to really observe children, identify problems, talk with parents, and teach staff.

Depending on local circumstances, day care programs may either provide certain services directly or assume a coordinating role, working with others in the community to assure that services are available and monitoring to see that the children receive them. In Pennsylvania, for example, an Interagency Task Force on Early Health Screening, established "to work out the kinks between EPSDT and other publicly funded programs for young children," was successful in increasing the proportion of eligible children receiving EPSDT screenings from 39 to 90 percent. In addition, a significant number of children in Title XX funded day care received preventive health services that they had formerly gone without (*25*).

In Auburn, Ala., the Head Start program qualifies as an EPSDT and a WIC provider. A health coordinator and a registered nurse arrange for and provide some health services, while the program contracts with physicians to do screening and provide corrective medical services. The program also works with church groups and foundations to provide transportation to health services, obtain food stamps, and ensure that handicapped children receive needed care (*26*).

Head Start programs provide particularly promising opportunities to improve health care for their target population, 3- to 5-year-old children from low-income families. Head Start is a comprehensive child development program providing education, health, and social services with a strong emphasis on parent involvement. Its health promotion activities for children are among the most successful supported by the Federal Government. The Panel concurs with a recent report of the General Accounting Office (*27*) that Head Start as a whole is a major success, and its further development offers one excellent vehicle for promoting the health of the Nation's low-income children. The health component of Head Start arranges for, or provides, a broad array of preventive, diagnostic, treatment, and rehabilitative services for enrolled children.

The Panel believes that the technical assistance and training component in health for Head Start personnel should be substantially strengthened in the future. In addition, Head Start funds available for health activities should be enlarged and formal agreements with Medicaid further negotiated to increase the funding for certain services such as outreach, dental care, preventive health assessments, and case management for followup care. The Panel also shares the enthusiasm expressed in the GAO report on Head Start regarding the Child and Family Resource program, a variant of Head Start involving special family needs assessment, case advocacy and case management superimposed on a traditional Head Start program. We concur that this model of comprehensive service delivery is a promising one to build on for the future. Because the Head Start health services component has developed and demonstrated the effectiveness of many of the foregoing recommendations, we believe that sharing Head Start materials and experiences with other child care providers would be extremely useful.

Day care centers and homes which receive Federal assistance through Title XX are another significant avenue for improving the delivery of health services to young children. These serve roughly 1 million preschool children each year and are subject to new regulations of the Department of Health and Human Services requiring that all participating children receive comprehensive health assessments, be up to date on immunizations and receive assistance in obtaining continuing health services, and that all providers meet standards for safety. So that these new regulations benefit children as they were intended, the Panel recommends the following steps be taken:

- *The regulations should be implemented promptly, with strong support from State health agencies and Title XX agencies.*
- *State Title XX funds should cover the costs to day care centers in staff time to implement the health component of the regulations.*
- *State health agencies should assist the State Title XX agency and day care providers in their efforts to arrange for necessary services for children in day care and to coordinate these services with the child's other source(s) of care.*

- *Federal interagency agreements should be developed among OHDS, PHS, and HCFA to encourage vigorous implementation and to find funds to pay for the assessments and followup care for those children not covered through other sources.*

Communities can take additional steps to link preschoolers in publicly funded or proprietary day care to health services and to other service networks. State agencies responsible for licensing day care providers should include basic safety standards and provisions for assuring that children receive health services as conditions for certification. In addition, schools, health care providers, and those community and State authorities with responsibility for monitoring overall patterns of primary care for children should be charged with establishing firmer links to the preschool and day care networks in their municipalities and States, and incentives should be provided for innovative health service agreements with day care and preschool programs.

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CHAPTER 7

DELIVERY PROBLEMS OF SPECIAL CONCERN

In reviewing arrangements for the delivery of needed health services to infants, children, adolescents, and pregnant women, the Panel identified a number of issues which offer special challenges or opportunities that cut across individual provider arrangements, and which we believe should be specifically addressed in the formulation of public policy. These include:

- Home visiting
- Primary mental health care
- Categorical services, including family planning and preventive dental care
- Mass screening
- Hospital care
- Regionalization

HOME VISITING

Home visits to families before and after the birth of a baby by nurses or lay visitors under nurse supervision is not a new concept. In a variety of forms and with a number of specific purposes, home visiting has been systematically undertaken in some communities in the United States and in many countries of Western Europe, often forming the cornerstone of organized efforts to improve maternal and child health. It was a more widespread phenomenon in the United States several decades ago than it is today, having fallen into disuse not because of diminishing need or lack of success, but apparently because funds and professional talents are increasingly concentrated on therapeutic and more technology-intensive services.

There is now renewed interest in a significant expansion of home visiting services. New and revitalized home visiting programs are under way in numerous communities in many parts of the country, with both public and private support, and under both public and private auspices. The Department of Health and Human Services has been exploring an expanded effort to promote home visiting programs. The American Academy of Pediatrics in June of 1980 sponsored a conference to examine and to highlight the potential of home visitor programs for improving the delivery of preventive health services to mothers and young children.

We believe this new interest reflects a recognition that:

- Many of the most important potential gains in child health status, given the state of today's medical knowledge, cannot be made without systematic and aggressive efforts to extend the reach of health professionals beyond the walls of their own offices and institutions and out to where the people most in need of services actually are.
- A growing proportion of problems in maternal and child health are rooted in the complex life situations of families. Much of the help pregnant women, young children, and parents need and are not getting—for example, in preventing accidents, nutritional problems, and child neglect and abuse—can best be provided in settings outside of major health institutions.
- As more providers of all kinds attempt to combine preventive and curative services, in order to enhance the quality, effectiveness, accessibility, and continuity of both, there is an increasing tension between the tasks of curing, and the tasks of health promotion. There is a search underway for a clearer focus for prevention-oriented activities, and for a way of assuring a reasonable allocation of resources to deal with the complicated interplay of social, environmental, and biological factors that are involved in effective disease prevention and health promotion.
- For many families in our mobile society, the traditional sources of support for pregnant women and new parents, including family and friends, are increasingly hard to come by.
- Some of the education in parenting skills which many new mothers used to get in the hospital during the days following birth is no longer provided because of a shorter hospital stay for childbirth (*1*). Furthermore, some medical problems, such as neonatal jaundice, may only become apparent after the baby goes home.
- In many areas, health services may be hard to locate, and systematic efforts are required to link people most in need with requisite services.
- Increased public investments in large-scale financing programs, especially Medicaid, while improving access to services, have not been sufficient to ensure that services are, in fact, received.

Most programs of home visiting now in operation seem to be the product of at least some of these forces. While the programs vary widely, most have the following characteristics:

- They provide information and help with making the home a safe and nurturing environment for the infant.
- They provide information and help with nutritional problems for the pregnant woman and infant.
- They provide certain basic health services (physical and developmental assessment, immunization) or arrange for them to be provided.
- They seek to assure that the pregnant woman and family are linked with an ongoing source of health services, and to social support services as necessary.

- They teach about basic health practices, and provide guidance about the most effective use of professional health resources.
- They assist families who need help in integrating the infant with the family structure and life style.
- Some seek to identify families at special risk and in need of special services.
- Some seek to personalize health services in ways that are difficult to accomplish in most health care settings.
- Some seek to enhance the parents' ability to stimulate the infant's social and cognitive development.

Some programs use nurses to make the home visits, some train lay persons who work under nurse supervision, and some combine these methods. Some programs emphasize the telephone availability of the home health visitor between visits. The programs have operated under a variety of auspices, including health departments, community health centers, hospitals, medical and nursing schools, and family drop-in centers. Most begin visits during the prenatal period, some limit services to the first year of an infant's life, and some extend them until the child enters school.

Some programs are universal, offering services to all infants and pregnant women in a given area, or to all where birth occurs in a given hospital. Others offer services only to high-risk families, with risk being defined socially (low income of family, social isolation, welfare eligible) or medically (low-birth-weight infant, discharge from infant intensive care unit). Some programs combine these concepts, offering services universally, but actively recruiting, or providing a greater intensity of services, to high-risk families.

The reported data on the effectiveness of home visiting suggests that it can be a highly effective form of intervention, especially when begun before the birth of the baby.

In a controlled clinical trial conducted in Montreal, families receiving prenatal as well as postpartum home visits experienced fewer home accidents, fewer problems with feeding and mother-child interactions, more up-to-date immunizations, and higher scores of assessment of home environment and maternal behavior (*2*). These measurable successes were far greater among those families where home visiting began during pregnancy than where it began after birth of the baby.

A home visiting program in rural Appalachia found that similar health outcomes were achieved for experimental and control children, although the former were at greater socioeconomic and environmental disadvantage; the experimental group also experienced lower outpatient utilization and lower costs (*3*).

In a controlled trial undertaken by C. Henry Kempe, M.D., and his associates in Denver, an experimental group of parents identified as being at high-risk of child abuse and neglect who received regular home visits by lay visitors and whose children received regular care by a pediatrician and a public health nurse did not abuse their children in the 2 years after the study began. In the high-risk control group of parents, at least five children were hospitalized with injuries thought to have been inflicted by parents (*4*).

A collaborative review of 14 early-stimulation programs found that they had major benefits in children's school performance several years later. Most of the programs reporting a substantial effect in reducing special education placement included a home component or were home-based (*5*).

While many of the people involved with these programs are distressed at the inadequate research attention home visiting has received, most agreed with the program director who told us, "I know that home visiting works, I know for sure it is one of the best tools we have to support families in nurturing and protecting their children. It would be criminal to withhold additional public support until that magic moment arrives 'when all the data are in.'"

The Panel is prepared to make a judgment about the usefulness of home visiting in the absence of more conclusive data because the existing evidence extends over many years and through many nations and cultures, and all point in the direction of effectiveness; because the unintended and unanticipated effects all seem to be positive; because the impressionistic evidence we have come across is extremely persuasive; and because the problems this form of intervention is aimed at are so urgent.

The Panel has concluded that Federal, State, and local authorities should increase substantially their support for home visiting programs as part of their efforts to improve maternal and child health. Such increased support must be of sufficient magnitude to:

- Permit a substantial number of States and communities to use home visits by public health nurses or other qualified personnel as one means of assuring access to needed health services for pregnant women and infants;
- Enable health departments, hospitals, comprehensive health centers, and other providers to establish or re-establish home visiting programs for women and infants at high risk, and ultimately for all pregnant women and infants, as a routine component of maternal and child health care;
- Allow for the evaluation of a wide range of prototype programs, to make possible the dissemination of new information about especially successful and cost-effective approaches to home visiting.

We consider it essential that new home visiting programs be made an integral part of other efforts to improve services to pregnant women and infants. Home visiting is not a panacea, and will not be effective in isolation, without links to continuing care for the family and organized backup and consultation for the home visitor. We see home visiting as a link to continuing care, not a substitute for it. We believe that participation in such programs by the pregnant woman or mother must be unambiguously voluntary, and all home visiting programs must respect family privacy and individual and cultural differences. If families are selected because of social need, they must not be pejoratively labeled.

The support of home visiting programs should come from special grants for this purpose from the Federal Government and private foundations, increased Title V funds, State and local revenues which are now supporting some of these activities, and Medicaid (through the use of waivers).

The costs of the kind of program we propose are relatively modest when compared with costs of other forms of health interventions, or when compared with the costs of treatment (including for neonatal intensive care) for conditions that an effective program of home visiting can often prevent.

Cost estimates of a fully implemented home visiting program depend on the size and nature of the target population, the degree to which lay visitors working under nurse supervision are utilized, and the number and nature of the visits. In order to provide some guideposts to policymakers and others regarding the general magnitude of costs for a revitalized program of home visiting throughout the Nation, we have made some rough cost estimates. Our calculations indicate that a nationwide program, utilizing public health nurses along with trained lay home visitors working under nurse supervision, could include all families with a high-risk pregnancy or high-risk baby, all low-income families with a pregnant woman or newborn, and all other families expecting their first child, for an annual cost of about $226 million. To cover only high-risk pregnancies and babies would cost an estimated $111 million per year (*6*).

While we believe there is sufficient evidence of the effectiveness of home visiting to justify public support that goes well beyond a research and demonstration phase, the Panel also considers it essential to refine available knowledge about the precise nature of the interventions most likely to work in various circumstances. This means expanded support of home visiting must be coupled with a reporting system and research design to generate answers to such questions as:

- What measures will provide a reasonable basis for evaluating the effectiveness of home visiting?
- Which of the various purposes that home visiting has been meant to serve seem most likely to be achieved?
- Which population groups are most in need of home visiting?
- Under what circumstances are home visits best conducted by nurses? By other professionals? By trained lay persons? How should these personnel be trained and supervised? What consultation do they require?
- What are the costs of achieving various purposes and of serving various types of families?
- When should home visiting begin in order to be most effective? Is it critical that it begin during pregnancy? Under what circumstances should home visiting continue beyond the infant's first year?
- What related services (such as hospital rooming-in, other efforts aimed at promoting attachment in the newborn period, and parent groups or drop-in centers) seem to be associated with or to enhance the effectiveness of home visiting? Does home visiting enhance the effectiveness of other services?
- What auspices (public or private; health department, health center, or hospital) for home visiting programs seem to be

optimal? Are there generalizations or guidelines regarding organizational auspices and effective linkages that could be applied nationwide?

- What factors determine the acceptability of systematic home visiting programs by the public and by potential recipients of the services? Is the acceptability and quality of home visiting likely to be higher if targeted on families in social, economic, or medical need, or if universally available?
- What factors determine acceptability and support of the program by relevant health professionals and institutions?
- Under what circumstances should third-party payers fund home visiting to pregnant women and infants as a standard benefit?

Several years of substantially increased investment in home visiting programs, coupled with proper evaluation, will provide the foundation for an ongoing program of maximum possible effectiveness at a minimum feasible cost. And we have no doubt that many families will have benefited significantly from the services in the meantime.

PRIMARY MENTAL HEALTH CARE

The Panel's public hearings, consultations, and studies left us disturbed and alarmed at the Nation's lack of progress in making appropriate and adequate mental health care available to all our citizens, including mothers and children. In addressing the organizational issues involved in the delivery of mental health services, we were struck by two major points:

- Many health problems which come to the attention of primary care practitioners are either emotional in origin or have important psychosocial components.
- A significant portion of what might be termed "primary mental health care" is in reality provided in general health care settings and in schools, day care centers, juvenile detention facilities, and other sites by personnel not specifically trained as mental health professionals.

These facts, unfortunately, are not adequately recognized at present in the organization and financing of services, in the training of many health professionals, or in arrangements to provide expert mental health support and consultation to parents, general health care providers, teachers, day care workers, social workers, correctional officers, and others who deal with children and their families day in and day out. We look to the new Community Mental Health Systems Act to help correct some of these deficiencies, but nevertheless consider it worthwhile to comment on the current situation, especially as it affects children, and recommend needed changes.

The Panel believes that more relevant, more responsive, and more appropriate mental health services are essential for the well-being of children, and that assuring the universal availability of such services will require a closer relationship between the mental health system and other sources of care for children. *We therefore recommend that policymakers*

and health care providers assign high priority to organizational reforms designed to achieve better integration of mental and general health care, and better coordination of the mental health system with other service systems, including education, corrections, and social services.

Integrating Mental and General Health Care

There is a growing recognition that mental and physical aspects of health care are inseparable and that this fact must be better reflected in our organizational arrangements for the delivery of primary care. In recent years, a number of expert bodies have come to this conclusion, including the President's Commission on Mental Health, the Institute of Medicine Conference on Mental Health Services in General Health Care, and the World Health Organization.

The need for greater integration of mental and general health arises from three sets of considerations. First, many individuals and families confronting emotional problems of varying severity seek care not from mental health specialists but from primary care physicians and other general health care providers. Often they come with a physical complaint, because physical and mental distress frequently coexist, because emotional stress can trigger physical problems, and because some parents and some youngsters view physical complaints as a more legitimate basis than emotional problems for seeking professional help. In addition, many people, fearful that they or their children will be labeled mentally ill or disturbed, and suspicious of mental health specialists, are simply more willing to seek and utilize care from general health care providers. Whatever the reasons, it is estimated that up to 60 percent of all persons with "mental disorders" are seen in the general medical care system (compared to 15 percent in the "mental health sector," and 22 percent not in treatment or being seen in other parts of the "human services sector") (*7*).

Second, many problems requiring psychological or social interventions—such as child abuse—are most likely to come to the attention of professionals in general health settings. Often, the moment of crisis which precipitates the visit to the physical health service is an opportune time for intervention, since people seem more amenable to changing unhealthy social or psychological practices at times of crisis (*8*).

There is a third reason why greater integration of mental health and general health care is needed. As discussed at length elsewhere in this report, effective primary health care—especially for pregnant women, mothers and children—increasingly requires expertise in recognizing and dealing with the psychological, social, and behavioral aspects of health. In responding to the needs of the family of a handicapped child for emotional and social support, or providing guidance to the parents of a "difficult" baby, or counseling a young teenager seeking a prescription for contraceptives, a primary care practitioner is actually providing what amounts to preventive mental health services. In helping a pregnant woman to stop smoking or drinking, or a diabetic youngster to adhere to a prescribed regimen, the primary care practitioner is applying an understanding of social, behavioral, and developmental precepts to prevent serious physical illness or disability.

Medical educators and professional groups, recognizing these trends, are making major efforts to modify traditional training and practice arrangements so that all types of primary care providers will be better equipped to deal with emotional, psychological, and behavioral problems and needs. Examples of such efforts include the Report of the Task Force on Pediatric Education, the appointment of an American Academy of Pediatrics Committee on Behavioral Pediatrics and the Family, revision of residency requirements for pediatricians and family practitioners to reflect the importance of such skills, and support by several private foundations of residency training programs in behavioral pediatrics (*9*).

Despite such positive steps, much remains to be done. Many primary care providers fail to recognize specific psychosocial disorders (*10*). Indeed, surveys of primary care physicians indicate they feel they were not adequately trained to recognize, diagnose, or treat either mental disorders or the emotional aspects of physical disorders (*11*). Not surprisingly, then, even when primary care providers do recognize emotional and mental disorders, their response to them is not always appropriate (*12*). Mental health professionals, on the other hand, may not always understand the interaction of psychosocial and physical processes, and how to coordinate treatment with primary care providers (*13*). Most mental health professionals work in settings where they are more likely to have links to more specialized mental health facilities than they are to primary care providers.

Barriers to better integration of mental and general health care are both sizable and firmly planted. Some involve differences between the two sets of professionals in personal and professional skills, styles, attitudes, and reward systems, and in their views of health and disease. Some have been created and reinforced by separate bureaucracies and advocacy networks, each jealously guarding its own "turf" and funding sources. Some stem from the reluctance of third-party payers to reimburse for any services other than well-defined technological procedures. And some result from the physical segregation of mental and general health care providers, which offers scant opportunity or encouragement for collaboration and consultation.

The structuring of primary care units to allow for a better integration of mental and general health care would increase the probability of prompt and accurate recognition of psychosocial problems as well as mental illness, and enhance the likelihood of prompt and effective interventions. It would also help primary care providers deal more effectively with psychosocial aspects of normal growth and development, and of physical diseases and injuries.

The Panel believes that the time is ripe for new and systematic efforts to organize and finance primary care—especially for children and pregnant women—in ways which will encourage adequate attention to psychological, social, and behavioral components of care and which encourage referral, consultation, and ease of communication between mental health professionals and primary care providers.

Where integration of mental and primary health care has in fact occurred, the results have been promising. The most recent and well-documented examples of successful integration come particularly from health maintenance organizations (HMO's) and community health centers. Although these delivery mechanisms account for only 2 percent of patients with mental health problems who were seen in the general health care sector in 1975 (*14*), their experience does demonstrate that integration is both possible and beneficial.

The existence of federally supported health programs and community mental health centers in the same community provides special opportunities to bring about close collaboration, opportunities that should be seized on by both programs at the local as well as the Federal level.

One program which has successfully integrated health and mental health services is the Bunker Hill Health Center in Charlestown, Mass., a neighborhood center established under the auspices of Massachusetts General Hospital, which offers primary care, mental health, social services, dental, nutritional, and other services to children and adults. The mental health program is a joint effort of the neighborhood health center (NHC) and the local community mental health center (CMHC). The CMHC provides the NHC with a child psychiatrist consultant, and organizational linkages between the NHC and the CMHC have ensured the provision of secondary and tertiary mental health services by the CMHC for patients seen by the NHC. Frequent communication between the NHC and the CMHC has facilitated coordination of specialized services for the mentally retarded and for children with behavior or learning problems.

Within the neighborhood health center, there has been active cooperation between general health and mental health providers. Integration of health and mental health services is fostered by the use of a single medical record and an effort to recruit staff with a commitment to and capacity for interdisciplinary teamwork. Vehicles for communication include consultation, inservice education, and a variety of collaborative programs to strengthen mental health skills of health providers and facilitate referrals of patients to mental health specialists when appropriate (*15, 16*).

Evidence of the effectiveness of such programs is beginning to accumulate. One study, for instance, found that combining health and mental health care significantly reduces referral appointment failures, increases feedback on referral results, improves informal contacts, and decreases stereotyping (*17*). Studies of 11 programs in HMO's and neighborhood health centers where mental health, alcohol, and drug abuse programs were integrated with general health care found significant cost savings after mental health care interventions, apparently due to a reduction of inappropriate use of medical care (*18–20*).

There is evidence that populations utilizing organized care settings such as HMO's and community health centers typically make greater and more appropriate use of mental health services than do those using other sources of care. This finding holds true for both children and adults. Perhaps this is because patients are more willing to accept mental health services when they are provided in a general medical setting (*21*), or perhaps it results from the special efforts some organized setings make to provide accessible, comprehensive and personalized care (*22*).

Coordinating Mental Health Services with Other Service Systems

The need for mental health expertise clearly extends beyond the health system to other settings where children live, play, and study. Children who need help—whether for transitory crises, serious emotional disturbance, or learning or behavioral difficulties which persist over time—are found throughout the education, correction, and social services systems. Yet far too often, the institutions which make up these systems have been ignored or abandoned by those with the greatest mental health experience and talent.

Teachers, day care workers, juvenile correctional officers, foster parents, social workers, guidance counselors, and others need far more collaboration, consultation, and support from mental health professionals than they are now getting in their efforts to help troubled youngsters. Help for disturbed children and adolescents is best provided in as near as to normal settings as possible, with the emphasis placed upon restoring the functioning effectiveness of families, neighborhoods, schools, religious and community groups, as well as upon enabling the young persons to respond to normal sources of support, affection, instruction, and discipline.

It is the Panel's conviction that mental health expertise available to institutions outside the health system, including schools, day care centers, foster homes, welfare and social service agencies, correctional institutions, and other youth-serving agencies must be substantially increased. A major role of highly trained mental health specialists should be to serve as collaborators, advisors, and consultants to a wide array of frontline workers with children and youth.

The schools offer a particularly important opportunity for applying mental health principles, precepts, and talents in a setting where both the immediate and long-term payoffs are likely to be great. The precursors of serious personality disorders are almost always apparent in the way children relate to schools. One study which followed hundreds of individuals from childhood into their 30's and 40's indicated the roots of violent and other antisocial behavior could typically be traced back to early childhood, particularly among boys, and that difficulties became more obvious and were more likely to be recognized once children entered school (*23*). Reading and learning problems, which usually surface in the school setting, are often associated with serious later difficulties. Some 75 percent of juvenile delinquents, for instance, are significantly behind their age peers in reading ability (*24*). The line between mental health problems and school learning difficulties is, however, frequently difficult to discern. Effective cooperation between the mental health system and the schools has become even more important with the advent of P.L. 94–142, requiring the public school system to provide an education to emotionally disturbed children, whether in regular classes or in special classes. Mental health professionals can collaborate with educators, and both can help children and their families in a variety of ways, such as:

- They can work together on the early identification of learning and emotional disorders, and the development of appropriate interventions for both.
- They can jointly counsel and assist the parents of children with learning difficulties, who may in the absence of such support develop feelings of helplessness and frustration which interfere with their children's emotional development.
- Mental health professionals can work with parents, teachers, and operators of day care programs to structure experiences for children at high risk for learning difficulties in a manner that minimizes the likelihood that secondary emotional difficulties will occur.
- Mental health professionals, educators, and preschool program personnel can work together to enhance their understanding of both the emotional consequences of learning difficulties and the learning difficulties experienced by children with emotional disorders.

The corrections and social service systems also need support from and interaction with the mental health system, both to improve services to individuals, and to design better programs and institutional arrangements.

For example, the problems of infants and small children whose mothers are or may be imprisoned could be dealt with far more effectively than they are in most places today if sentencing policies, prison practices, and the placement of children of prisoners reflected a greater awareness of the harmful effects of severed parent-child relationships.

Others likely to be in touch with the social service system, and who could benefit greatly from better arrangements to help them, are pregnant teenagers and young mothers who have run away from home or been pushed out of the family home. Most emergency shelters for runaway youth are specifically required by law to house no one under age 10, and therefore exclude young mothers with their infants. Young girls with babies are often left to fend for themselves or are referred to a social service agency which provides services on a walk-in basis, but these are often insufficient. For example, teenaged mothers who go on public assistance and set up housekeeping, often in an unfamiliar town, are known to have a high potential for child abuse, and may need more intensive services.

Some homeless pregnant women make use of homes for unwed mothers, such as those run by the Florence Crittenden Homes, the Catholic Charities, and the Salvation Army. Their numbers, however, are decreasing, as are the numbers of available facilities. Many such agencies and facilities are not equipped to help young people with multiple problems and no homes to which they wish to return. Most do not allow the mothers to remain more than 1 or 2 months after the baby is born, and make no provision for the continuing support of these high-risk mothers and infants.

Demonstration programs are needed to discover what works and what does not with infants, children, and adolescents who are in settings or situations where the risks to normal development are enormous, and who are already in contact with some public or private human service agency or institution. Much stronger connections are needed between the agencies trying to serve these young women and their infants and other sources of help, including health and mental health services.

One such demonstration is currently under way under the auspices of the Bronx (N.Y.) Psychiatric Center for children 3 months to 5 years of age whose mothers are emotionally disturbed, drug addicted, or otherwise in serious trouble. The program seeks to help these women become capable of responsible mothering, and to prevent functional disorders and learning disabilities in their children. Staff provides a support network to assist the mothers with problems of living and provide individual and group psychotherapy, classes on child development, and opportunities for therapeutic mother-child interaction. The staff also conducts a nursery school where children can develop a positive self-image, and works to ameliorate existing emotional and cognitive deficits (*25*).

Another example of better linkages is found at the Hill Health Center in New Haven, Conn. Some years ago, the community served by the health center accounted for over 20 percent of the referrals to the regional juvenile court, although it accounted for only 4 percent of the population of the region. At that time, few delinquents were seen at the health center, and most of those referred for treatment by the courts did not in fact receive care. The center determined that the services being offered were quite inappropriate, they were not valued by these youths, nor were they consistent with their "street" image. New programs were developed and subsequently large numbers of black delinquent youth became involved and received services through programs led by indigenous workers, some with police records in their own pasts, who have focused on naturally formed groups, street work, jobs, activities directed by the youths themselves, and advocacy with police, schools, and courts (*20*).

CATEGORICAL SERVICES, INCLUDING FAMILY PLANNING AND PREVENTIVE DENTAL CARE

As we discuss in other sections of this report, the Panel has found that primary health services for mothers and children are generally provided most effectively in settings that offer a comprehensive array of needed services. But there is persuasive evidence that some services are as well or better provided in settings that are not organized to provide comprehensive care. Such services tend to have one or more of the following characteristics:

- They are not dependent on continuity of contact with a single health provider (for example, the effectiveness of vision and hearing screening is less dependent on its being administered in a setting providing continuing routine health care than is developmental assessment).

- They can easily be offered in settings which attract individuals for other reasons (for example, certain health programs aimed at adolescents may best be provided in schools, teen centers, or places where many young people work).
- They are less closely related to other health or support services than are most health services (for example, little seems to be lost when preventive dental care is provided in a setting which does not provide other primary health services).

Two examples of service which meet these criteria and to which the Panel attaches high priority are family planning and preventive dental care. Although both can be and often are provided in comprehensive care settings, we find them especially well suited to being funded and provided as categorical services.

Family Planning Services

In previous chapters, we discuss the significance of family planning services in helping individuals and families to control the timing, spacing, and number of children they choose to have, and the need for family planning services to be made highly accessible. Toward this end, family planning services should continue to be available in many diverse settings—as an integral part of every primary care unit, and also in settings providing only family planning services, or only reproduction-related care.

People currently use family planning services provided by private practitioners (including obstetrician-gynecologists, family practitioners, and internists), and by approximately 5,000 clinics in both the public and private sector. The total number utilizing family planning services is unknown, but it is estimated that in 1977, those receiving care from private physicians included 2.2 million low-income women, and that 4.2 million women received care in organized programs. Of those receiving services in an organized program, 42 percent were served by health departments, 27 percent by Planned Parenthood affiliates, 14 percent by hospitals, and 17 percent by other agencies (such as free clinics, neighborhood centers, HMO's, university health services, and community action agencies) (*26*).

There is impressive evidence that this diversity of service settings and the prominent role played by categorical family planning services are major factors in the substantially increased number of women who today use family planning services. For many women, being able to obtain family planning services as part of continuing and comprehensive care makes these services more accessible and results in their more effective and appropriate use. For others, the opposite is true. The population seeking family planning services includes a large number of individuals who see their own needs as very different from those who rely on more comprehensive programs. The clients of family planning clinics are predominantly young, childless, and healthy. Some people whose primary concern is to postpone starting a family are reluctant to seek services from programs whose major concerns are family and child health, and care for the sick and ailing.

For many seeking family planning services, and teenagers especially, the critical needs are easy access to the facility, and guarantees that confidentiality and privacy will be protected.

Moreover, categorical funding of family planning services has resulted in allocation of funds which more closely approximate the actual need than is likely to be the case if authorizations for family planning programs were absorbed with other health services.

On the basis of these considerations, *the Panel recommends that categorical funding for family planning services be expanded to assure that these services continue to be made available in a variety of settings, and that all persons who wish to make use of family planning services, including counseling, will have access to such services.*

- Family planning should be an integral component of every primary care unit, but should also continue to be available in free-standing clinics and other sites of care which do not necessarily offer the full range of primary care services.
- State and local authorities should work closely together to assure that various sources of Federal support for family planning, including Title X of the Public Health Service Act, Medicaid, Title V, and Title XX of the Social Security Act, are used in ways which are complementary, mutually reinforcing, and congruent with national goals and priorities in maternal and child health.

The Panel urges expanded support of family planning services under Title X, Title V, Title XIX, and Title XX, with funding adequate to extend services to the 3 million low- and marginal-income women and 1.8 million teenaged women who are, according to estimates of the Alan Guttmacher Institute, still in need of subsidized family planning services.

Preventive Dental Services

Much more is known about the etiology of dental disease than of many medical diseases, and preventive measures are well developed and of clearly proven effectiveness. The oral health of adults is determined to a large extent by the preventive and treatment services received as children and by the oral hygiene practices and dietary habits they develop during childhood. Dental caries and periodontal disease, the two most common oral diseases of children are—for the most part—preventable (*27*). (For a discussion of the need for dental treatment, see chapter 5.)

The fluoridation of water (as recommended in chapter 2 of our report) has been characterized as one of the great bargains available in health care because of its effectiveness in preventing dental caries. An increased investment in additional preventive measures can be expected to result in a further reduction in acute and often disabling incidents of pain and discomfort, lower dental treatment costs, less disfigurement, clearer speech, and improved ability to eat healthful food—all important elements of health and well-being (*28*).

Effective prevention of dental disease requires both education and preventive services. These have been shown to be most effective when provided in a coordinated way—especially when the provider of the individual services reinforces the impact of the educational messages. The most important educational messages emphasize tooth brushing, flossing, and the reduction of sugar intake. The most important preventive services at the present time are the application of sealants, of topical fluorides if needed, cleaning, and screening examinations. *The Panel has concluded that certain basic preventive services are so critical to improving the dental health of the Nation that preventive dental services must be made available to all children.*

A prestigious study group of the Institute of Medicine/National Academy of Sciences has recently come to a quite similar conclusion, and has recommended that the first priority for action in dental health be the establishment of a new, school-based, publicly financed plan to provide preventive dental services and education to school-age children (*28*).

Many of the needed preventive dental services can be provided by auxiliary personnel in a group or classroom setting more efficiently and more economically than in any other setting (*28*). Many families, especially low-income families, do not now receive preventive dental care. More than one-fifth of all children between the ages of 6 and 16, and more than one-third of low-income children, had not seen a dentist in at least 2 years (*29*), and 12.3 percent of white children versus 26.0 percent of black children aged 4–17 years had never seen a dentist.

We therefore recommend that preventive dental services for children be made available in sites—such as public schools—which can provide substantial economies of scale, and which simplify access. The location of preventive dental services in schools or other sites where children regularly congregate has the added advantage that group educational services can be readily integrated or coordinated with the provision of the personal services.

There is ample evidence and considerable consensus that the provision of the preventive dental services we recommend *should involve the extensive use of dental auxiliaries.* There should be appropriate channels for referral if treatment is indicated. Parents and any family dentist identified for each child would receive a report on the results of the examinations, including the need for fillings or other dental care.

In communities where schools seem to offer the most promising site for these services, the program should be school based. The services could be provided under the auspices of health departments, community health centers, dental schools, or other community agencies or institutions, or perhaps even by schools directly. We believe that schools are more likely to offer appropriate premises for the provision of preventive dental care than for the provision of comprehensive health services (see discussion of school-based comprehensive health services, chapter 6), because we see fewer potential problems of community acceptability and relationships with other sources of care. This is because the necessary linkages to other sources of care and the needed interventions themselves are inherently simpler in the dental area. Also, a much higher proportion of needed services are not currently being provided by anyone, and there is greater agreement on what constitutes needed and effective services.

Regardless of auspices, the preventive dental programs we recommend should be established with appropriate parental involvement. *These programs should be funded through new Federal grants, and State and local revenues;* in addition, the feasibility of utilizing other sources of funds, including capitation lump sum payments from Medicaid and grants from ESEA Title I, should be explored.

The Institute of Medicine (IOM) study referred to above concluded that a program providing all school-aged children in America with dental screening, prophylaxis, fluoride application as needed, and sealants—all at appropriate intervals—along with health education-plaque control, would cost between $180 million and $360 million annually. (This estimate does not include the costs of capital equipment during the startup phase.) The IOM study indicates that the costs of delivering the same services in dentists' offices on a fee-for-service basis would be significantly higher (*28*).

While we advocate that this program be universally available, we urge that first priority be given to communities with large numbers of children who lack access to routine dental services—that is, communities with a high proportion of poor children, and some rural communities.

The case for a nationwide program to provide school-age children with preventive dental services applies also to preschool children over age 3, especially with regard to the education component. Eighty percent of children whose families have incomes under $6,000 have not seen a dentist by age 6 (*29*). To begin to make some inroads on this problem, the Panel recommends that as community programs of preventive dental care are established, children in day care centers, day care homes, Head Start, and other preschool programs, be eligible to receive preventive dental services through these programs, and that the community programs work with providers of care to preschool children to assist them in providing preschool children with the educational component of the program.

If community preventive dental programs are not immediately established, special provisions should be made to assure the availability of preventive dental services to preschool children, including bringing dental teams to day care centers, or bringing day care children to dental clinics.

PERIODIC MASS SCREENING

Screening for the presence of disease or its precursors has of course always been an integral part of health care. Health histories, physical examinations, and routine laboratory tests all represent various forms of screening. Testing of newborns for a variety of problems, including congenital and genetic defects, is a particularly effective form of screening. Some kinds of screening tests, such as vision testing in the schools, have long been performed in other than health care settings by personnel other than physicians. Over the last decade there has been a substantially increased interest in and experience with the large-scale application of a combined battery of several screening tests, in settings other than the usual source of care.

Multiphasic screening, as organized mass screening for a variety of conditions was originally called, promised to be an extremely efficient way of allocating scarce medical resources. By utilizing inexpensive tests and relatively inexpensive personnel to sort out—from an apparently well population—those persons in need of diagnosis and followup care, it was hoped that screening would assure early intervention when it was most effective, and would go far toward keeping the so-called "worried-well" out of the health system. The Kaiser-Permanente Health Plan pioneered the use of multiphasic screening among members of the longshoremen's union, and found that it was an effective and economical way to improve the health status of its subscriber population. Since the screening was done in the longshoremen's union hall, and since all those screened were enrolled in a comprehensive health program, most of the problems that plagued later efforts at mass screening, including those of getting people to come in for screening, and assuring effective followup, simply didn't arise.

The largest single impetus for organized screening programs in this country came in a very different context about 15 years later, in 1967, when the Congress amended Medicaid to require States to provide "early and periodic screening, diagnosis, and treatment" (EPSDT) to all children under 21 who were eligible for Medicaid. The enactment of EPSDT was recommended by a Department of Health, Education, and Welfare (DHEW) task force that had been asked to look into the striking prevalence of chronic handicapping conditions which had been revealed by a Selective Service study. More than 15 percent of 18-year-olds had been rejected for the draft because of hearing, vision, dental, orthopedic, emotional, and developmental problems. The DHEW group estimated that 62 percent of these conditions were preventable and correctable through comprehensive and continuous care, and at least 33 percent through a program based on periodic screening. The latter was chosen as the most cost-effective route (*30*).

The assumption on which the enactment of EPSDT was based—that the Nation could save money and that children's health could be improved by providing targeted, limited services which had high payoffs in finding costly, crippling illnesses—has proven to be largely false. The effectiveness and economies of finding, identifying, and ameliorating serious conditions within the constraints of a program that provides screening services largely in isolation, and does not have the capacity to deal simultaneously or under the same auspices with all the health needs of a child, turned out to be illusory. Health professionals were frustrated in trying to utilize a one-time screening to discover the myriad conditions that reveal themselves over time. Families seemed reluctant to use providers who offered only screening tests which professionals had decided were important, while not being in a position to respond to the health needs that the family considered important.

As the EPSDT experience demonstrated, and as current efforts (incorporated in CHAP legislative proposals) to replace EPSDT with a program emphasizing continuity of care reflect, a program of mass screening and followup is a poor substitute for access to ongoing, comprehensive health care.

A particularly problematic aspect of mass screening has been and is the matter of developmental assessment. On the one hand, early identification of developmental problems can be extremely useful in ameliorating them and in warding off secondary complications. On the other hand, reconciling the complexity of development with the simplicity of screening is enormously difficult. Screening, after all, uses quick, simple procedures and tests capable of a pass-fail interpretation to identify children in need of followup diagnostic tests or care.

The major strength of mass screening is to detect problems that can be found and treated without reference to social, environmental or cultural issues. Some problems—vision and hearing deficits, speech impairments caused by physiological malformations, and some delays in motor development—lend themselves more readily than others to the mass screening process. However, many developmental problems—especially those involving the complex interaction of physiological, cultural, environmental, and emotional factors—are easy to misjudge in a quick screen. One cannot accurately find the child who is hyperactive, disturbed, or retarded by the administration of a quick, simple test. These problems call for the clinician to pull together information from many different sources (physical examination, health history, specific laboratory or other test, observation of the child, talking with parents) obtained over a period of time to determine whether a sign or symptom is transient and minor, or one of lasting significance.

Because of the difficulties encountered in implementing the developmental assessment part of the EPSDT program, the Task Force on Infants, Families, and Children of the President's Commission on Mental Health and the Children's Defense Fund both concluded that developmental assessment should take place only in the context of a comprehensive health assessment (*30, 31*).

The study of early screening programs undertaken as part of the landmark report on "Categories, Labels, and Their Consequences," published in *Futures of Children*, also concluded that, "Routine health and developmental care should provide the context for identifying developmental difficulties of children." In recommending improved procedures for early identification of children at developmental risk in *Futures of Children*, Nicholas Hobbs writes, "Our primary concern is that a substantial and sustained investment in screening programs may result in delay or even indefinite postponement of the development of a satisfactory health program for the Nation's children" (*32*). The report's recommendation that screening for developmental difficulties should be provided in the routine delivery of health care by providers who can be the source of followup treatment is coupled with the recognition that screening programs are preferable to no contact with the health system, and that more research is thus needed to determine the usefulness of

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various kinds of screening procedures and to deal with the problems of false positive and false negative findings which may emerge from screening.

The Panel believes that mass screening, especially for physical problems, can be an extremely useful *supplement* to comprehensive care. Selected tests compatible with the techniques of mass screening, such as those for anemia, vision, or hearing problems, could be performed at a few specified intervals: for example, once during infancy, once before entering elementary school, and once before entering junior high school. Such screening could provide a check on the adequacy of the care being provided to children and would assure that at least those conditions which one-shot screening can reliably detect would not go unnoticed. More important, such screening could identify children without regular health care and could trigger efforts to link them to sources of continuing care.

The Panel considers developmental assessment a key component of the health assessment of every child. We also agree that developmental assessment of young children is not properly performed as part of a mass screening program, and should be carried out only in the context of a more comprehensive health or educational assessment. *Policymakers and health care providers should base the design and operation of programs that involve screening on the assumption that screening is useful when screening tests are performed (a) in the context of individual assessments and continuing care, (b) as a means of detecting a limited number of conditions characterized by simplicity of detection and followup, (c) as a way of linking children to an ongoing source of care, or (d) as a check on the adequacy of care which children are receiving. Parents should be involved at every stage of the process.*

- State laws mandating school screening programs should be modified where necessary, and implemented so as to assure that they result in more than perfunctory and isolated screening tests. School authorities should use the occasion of any physical examinations and vision and hearing screenings they may be required to do as an opportunity to identify those children without regular sources of primary care, and take the steps necessary to link the children and their parents with such care sources.
- In the implementation of the EPSDT program, Federal and State Medicaid authorities should assure that all children with identified health problems actually receive diagnosis and treatment, are linked to a regular primary care source for subsequent services, and that parents retain responsible roles in their children's continuing care.
- The Board on Health Services Standards should review periodically what screening tests can usefully be provided as a supplement to comprehensive care for all children, and which screening tests (for example, lead poisoning and tuberculosis) should be provided to high-risk groups only; at what stages of life they should be given; and under what auspices they are most effectively administered.

INPATIENT HOSPITAL CARE AND EMERGENCY CARE

Psychosocial Aspects of Children's Hospitalization

Only a small fraction of children's illnesses or accidents require inpatient hospital care for proper treatment. Despite the higher incidence of acute conditions among children, children have proportionately fewer hospitalizations and shorter hospital stays than adults. In 1978, just 6.9 percent of all children under 15 years of age (excluding newborns) experienced a short-stay hospitalization. Others, suffering from congenital defects, developmental disabilities, and chronic medical conditions require long-term followup care and frequent hospitalizations.

Effective care of the hospitalized child, to an even greater extent than that of adults, requires careful attention to the child's physical and psychological needs. Special organizational arrangements are required to ensure that these sets of needs are adequately met. Illness alone may exact a great emotional toll from the child and family. An illness necessitating a hospitalization becomes a major experience in the life of a child and family. Many of the events which often accompany a hospitalization can become additional traumas and sources of stress. These may include separation from parents and siblings, disruption of daily routine, immobility, anxiety about the medical encounter, and being poked, prodded, and punctured, seemingly without end (*33, 34*).

Accidents and chronic or severe illnesses may leave psychological scarring as well as physical disfiguration. Child psychiatrists, psychologists, social workers, clinical nurse specialists, and child life specialists can support and supplement the efforts of the parents, the primary care provider, and the attending specialist in helping children to cope with physical and emotional pain and distress. Parents can also be supported in coping with their child's hospitalization, and in helping to reintegrate the child into the family and to re-establish peer relationships after a lengthy hospital stay.

The key to successful management of all child health problems requiring hospitalization is a synthesis of medical-surgical expertise with a thorough application of principles of child development. When psychosocial support systems are built into the delivery of care, physical recovery is hastened, and there are fewer psychological problems (*35, 36*). Attention to the human side of hospital care is not just good medical practice; it is also preventive medicine and it is cost effective (*37, 38*).

Hospitals have made great progress over the last two decades in adapting their environment to reflect a heightened understanding of the developmental and psychosocial needs of children and families in health care settings. A substantial number of hospitals have already taken the steps which the Panel believes that all hospitals which offer pediatric care should take. *The hospital's commitment to children should be reflected in operating and staffing policies, environment and design of space, and philosophy of care.* To make hospitalization more humane and to improve health outcomes, all hospitals which offer pediatric care that have not already done so *should adopt the following policies:*

- *Encourage, support, and provide accommodations for parents to stay with and participate in the care of their hospitalized child.*
- *Allow parents, and siblings as feasible, to visit hospitalized children at any time.*
- *Make systematic provision to prepare children and their parents for hospitalization of a child and for major medical or surgical procedures.*

Hospitals that do not at present have such arrangements are often constrained by budget and space considerations. *The Panel believes that the costs of basic psychosocial care, including preadmission and other activities aimed at preparation and support of child and family, should be part of the hospital's per diem rate, reimbursable through third-party payment in the same manner as are the costs of medical, surgical, nursing, and clinical dietary services.* We also recommend that the presence of these arrangements be considered in the process of determining hospital accreditation, and that, to the extent that they are reflected in the allocation of space, hospital construction eligible for Federal loans be required to make appropriate provision for the special needs of children and their families.

Recent hospital cost containment efforts have resulted in increasing concern with establishing suitable utilization standards for hospital admissions and duration of hospital care (*39*). While recognizing the importance of fiscal responsibility, the quality of care should not be compromised. "The need to hospitalize a child is dependent upon the special services which the child requires rather than upon the diagnosis" (*40*). It is frequently necessary for a child's welfare to hospitalize him or her because the home is inadequate for the circumstance of illness. It is necessary that auditors and PSRO's have a full understanding of this so that hospital beds for children are used appropriately, in a social as well as a medical context.

Criteria for length of hospital stay of children for particular types of surgery and illness should be established to eliminate unnecessary hospitalization, while including individual psychosocial needs as valid criteria for lengthening or shortening a child's need for hospital care. For chronically ill and handicapped children, hospice care or other means of care outside the hospital should be available, whenever possible, at home or in a setting closely approximating home.

Hospitalization for Childbirth

Major attention should also be given to the childbirth hospitalization experience. Educational and supportive programs for expectant parents can help foster better care. An increasing number of hospitals with obstetrical departments are today offering educational programs, professional support, and the physical setting for family-centered newborn and maternity care. This trend should be encouraged, and traditional practices and routines should be reassessed in light of new knowledge and experience; hospital staff should become better informed about family-centered care (41). The Panel notes the need for sensitivity, and accommodation wherever possible, to the physical, emotional, and social needs and desires of the mother and her family or significant others during the childbirth experience.

We recommend that all hospitals that offer obstetric care, if they have not already done so, adopt the following policies: *Arrange for or sponsor childbirth classes for prospective parents; permit the presence of the father or other supportive person in labor rooms and at routine deliveries, and enable them to play a supportive role in the childbirth; make it possible for newborns to room in with their mothers; make special arrangements to maximize contact between newborns and parents, especially if the infant requires intensive care; adopt a liberal visiting policy for children of maternity patients.*

Even as more hospitals move toward providing more family-centered obstetric care, there is and will continue to be a demand for childbirth in free-standing birthing centers and at home. More than 75 birthing centers are operating in the U.S. today, compared to only 6 just 5 years ago. Sixteen of these are free standing, and the rest are hospital based (*42*).

The Panel notes that these developments are consistent with its hopes for a wider availability of family-centered care of all kinds, and believes that all relevant institutions, including third-party payers, should adapt their practices and policies to permit these alternatives to flourish to the extent that they are consistent with the provision of high-quality care. Because this has become an issue of much debate, especially with regard to free-standing birthing centers and home births, we strongly encourage further research and data collection to allow assessment of different birth practices with respect to safety, cost, quality of maternity care, and optimal environment for family interaction and development.

Hospitalized Newborns

Low-birth-weight or otherwise handicapped newborns who remain in the hospital long after their birth are infants at very special risk. Increasingly sophisticated technologies have saved a dramatically increasing number of low-birth-weight babies, many of whom must remain for weeks, or even months, subjected to very abnormal environmental conditions, including separation from parents. To the extent possible, hospital practices should encourage contact between parents and the infant. However, the opportunity for parents to have close contact with their infants in the hospital will often be limited, and they may have trouble relating to them when they are ready for life at home. Training for physicians and nurses in perinatal care units should inculcate understanding of the psychosocial aspects of the risks these infants face, develop skills to work with parents to minimize these risks, and encourage establishment of strong linkages to sources of continuing psychological and social supports for the families.

Emergency Care

In many communities, one of the major deficits in child health care is the lack of accessible modern medical emergency services. Many children come to emergency rooms each year because of accidents or injuries. Others come because they have no regular source of continuing care. Children may be referred to emergency rooms by their regular provider when they need care at night or on weekends. More than half the emergency rooms in the country do not have a pediatrician on call (*43*). Their staff has no special training in managing childhood emergencies. They often unnecessarily separate a child from the parents at the very moment when support is most needed. The sights, sounds, equipment, and treatments in an emergency room may frighten anyone; they can be overwhelming to a young child, who has little comprehension of their beneficial purpose.

All hospitals with emergency rooms which treat children should assure the availability of special pediatric equipment and of medical and nursing staff knowledgeable in the care of critically ill or injured children, and in the use of pediatric equipment; arrangements surrounding the provision of emergency care should reflect sensitivity to the special needs of children.

Those that see a relatively large number of children (perhaps more than 50 in a 24-hour period) should keep a separate physical area for children, away from the sights and sounds of the adult services, and should have special personnel, especially nurses, available to care exclusively for children.

In addition, all hospital emergency rooms should establish mechanisms for encouraging patients and their families, if they do not have a regular source of primary care, to select and use one and—to the extent consistent with the preservation of privacy and confidentiality—should assure systematic transmittal of medical information about emergency visits to the patient's primary care provider.

One good way to convey the necessary information from the emergency visit to the patient's primary care provider, is to give it to the patient or parent. This has the virtue of not only getting the record conveyed safely, but simultaneously serves to provide the patient and family with important information.

REGIONALIZATION

"Regionalization" in its broadest sense implies the ordering of health resources and services within a given area to promote efficiency, avoid unnecessary duplication, improve access to health care, achieve greater equity, enhance quality, and respond to consumer needs. During this century, there has been a gradual movement in the United States toward regionalization of specialized, high-technology services in particular. While its potential has not always been realized in practice, the Panel believes the principle of regionalization has much to commend it. More efforts are needed to assure children and pregnant women, and indeed all Americans, access to specialized services, many of which must be concentrated in regional centers if the expensive equipment and facilities and highly skilled personnel associated with them are to be available.

Health planning legislation enacted by Congress in 1974 was designed to promote a comprehensive assessment of population health needs within a defined area and a more rational allocation of all available health resources within each area. It has not, however, as yet lived up to its potential. Thus, our only extensive experience with regionalization remains concentrated in the area of specific components of care and certain special-purpose institutions. Examples of the former, in the maternal and child health sphere, include the Crippled Children's program and perinatal care, while the latter is typified by children's hospitals.

The Crippled Children's Services program was established, under Title V of the Social Security Act in 1935, to develop a system of care for handicapped children and to treat conditions which might lead to handicaps. Characteristics of this regionalized program include the development of a State plan, case management from case finding through diagnosis, treatment, and aftercare; an interdisciplinary approach; traveling clinics with personnel from tertiary centers; approved providers and hospitals for specific services; prior authorization for care; voluntary organization and community support; and a Federal-State sharing of costs. An important element has been the involvement of the private provider sector in planning, guidance, standard setting, and the provision of direct services.

The greatest recent activity in regionalization has been in perinatal services. As long ago as 1947, sick newborns were transferred from other area hospitals to Children's Hospital in Denver. In the 1950's in New York City, 16 premature centers were developed at both voluntary and municipal hospitals to care for small infants at risk who were born at over 70 hospitals with maternity services. The transport of these prematures was handled by the Premature Transport Service of the New York City Department of Health. A knowledge explosion in perinatal physiology and pathophysiology began in the 1960's. Criteria for establishing a regional newborn center were developed at a Children's Bureau meeting in 1966 and included: (1) approval and support of regulating agencies of the State; (2) full-time nursing and medical personnel; (3) 24-hour supporting services; (4) 24-hour consultation services; (5) transport services; (6) life support monitoring equipment; (7) continuing education program; and (8) full commitment of board of trustees, administration, medical staff, and community.

A major impetus to the regionalization of perinatal services was the publication in 1976 of *Toward Improving the Outcome of Pregnancy*, by the National March of Dimes Birth Defects Foundation. This document contained recommendations for regionalization of perinatal services developed by representatives of the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, and the American Medical Association. Another important impetus was the funding provided by the Robert Wood Johnson Foundation to establish model perinatal centers and to evaluate their impact.

Children's hospitals are important examples of regional institutions with a vital role to play in meeting the health needs of children. Not all hospitals can or should provide all services to all children. Children's hospitals, which are typically located in the central core of large metropolitan areas, serve as major referral centers for a wide geographic area in the provision of specialized care for infants and children. Because of their center-city locations, they are also usually deeply involved in providing primary care to medically underserved populations, and generally have heavy teaching and research commitments as well.

In general, regionalization of services—whether designed specifically for children or to meet designated health care needs of individuals of all ages—is most important for complex, often expensive services which require special skills to provide appropriately. The list of such services will change over time, and as the capacity of more providers increases to deliver a particular service without loss of quality and at an economical price, that service can be spread beyond its original regional center locus.

Federal and State authorities, professional and voluntary organizations, hospitals, medical schools, and the public at large should actively support the development of selected regionalized health services for children, newborns, and pregnant women. Among the specific steps which should be taken are:

- Further development of regionalized perinatal care networks to assure all high-risk pregnant women and newborns access to regionalized care systems
- Encouragement of the trend toward regionalized genetic services, including pooling of laboratory diagnostic facilities and the availability of consultation
- Extension of regionalized networks to improve care for serious accidents (burns, trauma), certain chronic illnesses, and handicapping conditions, and to make more widely available various other forms of technologically demanding medical care for seriously ill children
- Support for regionalized backup and referral services for diagnosis and treatment of children with chronic illness, handicaps, or psychosocial problems
- Development of better methods of communication between medical centers and primary care physicians so the latter can provide appropriate followup services
- Support for improved regionalized ambulance services
- Enlarged public and private support of children's hospitals in their role as regional resource centers and providers of specialized care.

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CHAPTER 8

ORGANIZING SERVICES FOR SELECTED POPULATIONS

There are four special populations of children with health problems that present a unique challenge for the effective organization of services. These include adolescents; chronically impaired children; children in foster care or other out-of-home placements; and children with serious access problems as a result of language, cultural, and lifestyle variations from the mainstream of society. In this last category are the children of migrants and seasonal farm workers, Native Americans, refugees, and illegal immigrants.

ADOLESCENTS

In reviewing the problems faced by certain special groups in obtaining adequate and appropriate health services, the Panel's attention was frequently directed to the unmet needs of the Nation's adolescents—those young people approximately 12–17 years of age who, in this society, occupy a special and often stressful life stage between the dependency of childhood and the independence of adult status. Despite the prominent position of adolescents in our youth-oriented society, the development and deployment of health services reflects inadequate attention to this group.

Adolescents share with other underserved groups inadequate access to needed health services. This is true not only for services important to all age groups, but also for those of particular salience to teenagers, such as family planning, drug and alcohol abuse prevention, and various forms of counseling. Moreover, to the extent that health services are available to teens, they almost always tend to be oriented more to problems rather than normal growth and development.

There are a variety of reasons for the failure of the health system to address the needs of adolescents adequately. Certainly a major one is that, in a strictly medical sense, adolescents are healthy. Their death and illness rates are lower than for adults and infants—the illnesses and life-threatening conditions of infancy and young childhood are generally past, and the chronic disabling conditions of adulthood are not yet manifest.

To a greater extent than for other age groups, their health problems tend to be based more in emotional and psychological dimensions than in physiological ones. Because, as noted earlier in this report, the current health system does not deal effectively with the psychological, social, and behavioral aspects of health, it is not surprising that adolescent health needs are often ill-served. The emphasis of third-party reimbursement on disease treatment and care rather than preventive services and counseling, which are highly relevant to adolescent needs, limits the effectiveness of the health system in helping adolescents. So does inadequate information about the most effective ways to design services for adolescents; a lack of consensus about the appropriate division of responsibility in this area between the schools and the health system; and a lack of clarity about which medical specialities are responsible for adolescent care.

The Panel believes that the relative neglect of the health service needs of adolescents at present is neither defensible nor necessary. *We recommend that policymakers and health system leaders give increased attention to the health needs of adolescents in existing health service systems, and that both public and private sectors intensify their efforts to develop and refine new models of organizing services to meet the special health needs of this important life period.*

Health services for adolescents should be designed with two key factors in mind. The first is the significance for health of a variety of behaviors characteristic of adolescence; the second is the various attitudes and preferences of this age group. Both of these factors are taken up in detail in chapter 3.

As discussed there, one of the great challenges in meeting the health needs of adolescents is to recognize the prominence of personal behavior issues in the range of health problems affecting this group. This is not to say, of course, that the full range of medical problems are absent in this period. Like younger children and adults, adolescents have important medical problems—cardiovascular diseases (including hypertension), diabetes, malignant neoplasms, respiratory infections, dental diseases, hearing and vision disorders, and other problems. Adolescents are also not immune to the burdens of physical and emotional handicaps and chronic illnesses. But, as a group, they are unique in the extent to which health-related behaviors are of overriding significance for both short-term and long-term health status.

The way in which health services for adolescents are organized and provided must also be in tune with a number of preferences and attitudes characteristic of this life period, such as the significance of peer relationships. Attitudes, values, and behaviors are likely to be modeled on those of the social group. Adolescents are generally immersed in the present, often lack a tangible sense of future consequences or possibilities, and typically feel that, even if they are not quite immortal and indestructible, they certainly won't be the ones to be involved in an accident, get gonorrhea, or become pregnant. When and if they seek help from health personnel, teachers, religious advisers, or any other source, they are intensely concerned that their privacy and confidentiality be respected. For the health system, and indeed all institutions, it is a special challenge to respect and accommodate the teenager's desire for privacy and confidentiality in a manner that simultaneously strengthens and supports parental involvement with teenage children.

Desirable Service Characteristics

Given these various characteristics of adolescence, the Panel has identified certain attributes that should be incorporated into the design of health services for this age group. These pertain to outreach, education and counseling, privacy and confidentiality, and financial barriers.

Outreach

Adolescents are often unfamiliar with the health care system and cannot be effectively reached through their families alone. Even more than adults, they generally require special outreach efforts to acquaint them with the health system and to get them to use services appropriately. *Outreach systems for adolescents should be provided through the settings where they spend much of their time—in school, youth centers, shopping malls, and the like; through youth-oriented media, and through health facilities such as family planning or drug abuse clinics which may serve some of their peers.*

Education and Counseling

The importance of education services that occur in schools and other community settings is described in some depth in chapter 3. Here we would only add that *once an adolescent comes in contact with the health system, educational efforts should continue to constitute a central component of the health services offered. Such education efforts should be developmentally appropriate and, as with community-based health education for adolescents, use materials that are suited to the values and preferences of adolescents and build, as appropriate, on the importance of peer influences.*

Related to education, and of equal importance in organizing services for adolescents, is a strong capacity for counseling services. Indeed, in areas such as family planning, the counseling components of care are of equal importance to whatever medical services are delivered. Given the many vulnerabilities of adolescents, and their many questions and concerns about a number of health matters, counseling should, like education, be a major aspect of most adolescent health services, especially family planning services and others related to sexual activity. The general importance of counseling services is described in more detail in chapter 5.

Privacy and Confidentiality

Privacy and confidentiality are paramount concerns of young people and must be so recognized by the health system. *As a general principle health services—particularly family planning and other services related to sexual activity—should legally be available to adolescents without parental consent and with full assurance of privacy and confidentiality.* This does not mean, of course, that parents and families should be excluded from the health care decisions of adolescents. Every effort should be made to encourage young people, and especially younger adolescents, to communicate with their families about any care they are receiving. However, requirements of parental involvement must not be permitted to become a deterrent to the receipt of needed services, nor should receipt of services be contingent upon parental consent. Outreach messages must make clear that help is available on a confidential basis; information must be held confidential and released only with the young person's consent; and confidentiality must be protected in establishing fees and billing for services.

Financial Barriers

Most adolescents have limited access to money, especially money they can spend as they wish without an accounting to their parents. Thus, even when they are guaranteed confidentiality in obtaining health services, they may be deterred from seeking needed services by financial constraints. *The Panel's general view that financial barriers should be reduced or eliminated to increase the availability of needed health services holds especially true for adolescents. Services to this population—especially those often sought independently such as venereal disease diagnosis and treatment, family planning, pregnancy testing, and crisis counseling—should be available either free or at reduced cost, using a sliding fee scale or similar structure.*

Another important consideration in designing health services for adolescents pertains to the personnel who come in direct contact with the teenagers seeking care or information. *Health services designed for adolescents must place a high premium on using staff who are sympathetic to the needs and styles of teenagers and communicate well with young people.* This view—all but self-evident on the surface—has recently been supported by a study commissioned by DHHS which indicated that adolescents were primarily concerned with the presence of nonjudgmental, sympathetic personnel, and with privacy (*1*).

Organizational Models

As for all age groups, health services for adolescents can be organized in a variety of ways, even when incorporating all the system attributes noted directly above. The traditional medical mode of health care delivery remains a major source of care for adolescents with overt health problems. This system—typically including private physicians' offices, general ambulatory facilities, inpatient hospital units, and the like—is most familiar to parents and indeed many health professionals. However, its value for adolescent health is limited because in general a teenager is ill before contact is made, thereby restricting the number of adolescents included in the system because morbidity is low in this age period. This disease orientation also limits its value in the broader preventive education and counseling activities so important to adolescents.

Services to adolescents at present include various categorical programs such as teen family planning clinics and drug or alcohol abuse programs targeted at teenagers. It is the Panel's view that in some instances, such categorical programs are appropriate and efficacious. Family planning services for teens are a good example, responding to a specific need with a specialized program. All such programs, however, need strong referral networks so that adolescents may be put in touch with other services that they need.

In addition to categorical programs, the Panel sees great value in a multiservice team approach to health care that addresses basic issues of adolescent development such as risk-taking behavior. Health-compromising behaviors in adolescents tend to occur simultaneously; for example, adolescents who smoke are more likely to experiment with alcohol than those who do not smoke. An overall tendency toward experimentation that characterizes adolescence is not specific to any single behavior, but underlies almost all the health-compromising behaviors considered here.

An example of an integrated, multiservice approach to adolescent needs is The Door in New York City, which combines in one place a wide variety of services for adolescents—not only health, but also recreational, vocational, and other services (*2*). Because so many types of services are offered in such multiservice models, the problems of funding (usually provided categorically) can be especially difficult. Each service of the facility may be supported or regulated by different sources who themselves require different reporting, licensing, or monitoring procedures. The lack of health professionals trained in such interdisciplinary approaches may also create staffing problems.

Services to adolescents are also delivered in non-health care settings. Certain institutional settings are discussed later in this chapter. Interest is currently high in using the schools as delivery sites for health services to adolescents and younger children. In some communities, schools are a logical site for providing both health services and health education.

In reviewing the many models currently providing health services to adolescents, the Panel was struck by the indisputable value of promoting a range of systems through which an individual may obtain the services he or she needs. So, as for children and pregnant women generally, the Panel *recommends that policymakers, public and private third-party payers, and other decisionmakers support a variety of models for providing services to adolescents to accommodate the multiple and varied needs of this group and to present diverse opportunities to establish connections to the health care system.*

We emphasize that it is not necessary to establish whole new systems of care for adolescents. Indeed, it is the Panel's strong view that *the cause of improved adolescent health would be significantly advanced if existing health services systems and programs were to pay increased attention to this special life stage and organize services for this group appropriately.* For example:

- Acute care hospitals with a significant number of adolescent patients should organize adolescent units as distinct from pediatric and adult services, and provide such units with counseling, recreational, and related support services appropriate to adolescents.
- Family planning clinics that serve significant numbers of adolescents should provide special clinic sessions for teenagers that

emphasize education or counseling, are sensitive to other needs adolescents might bring such as drug problems, and include a vigorous outreach program to area adolescents.

- Private physicians, especially pediatricians, caring for adolescents should ensure that their routine patient evaluation procedures for teenagers include not only a medical history and a physical exam, but also a review of pertinent health habits, peer and family relationships and related behavioral issues. Systems should be available for referring adolescents, as appropriate, to other needed services such as mental health services or drug abuse services.

And in all such settings, sensitivity to adolescent needs—manifested, for example, by placing services at times and locations suitable for school schedules and staffing services with personnel specially trained or suited to communicate well with adolescents—may well be more important in designing successful and useful services for teenagers than the particular organizational delivery model chosen.

In the public sector two existing programs—EPSDT and Title V—are in place and able to help with a variety of adolescent health needs but in general have failed to do so. The EPSDT program is designed to provide regular screening and health treatment for children and youth under 21 who are Medicaid eligible, but in practice the program has been oriented to infants and small children. The picture is not much different in the Title V program, where young people up to the age of 21 are eligible for a broad range of services but the focus is on the very young. Of the relatively small portion of adolescents receiving any care financed by Title V, considerably more than one-half are seen only for pregnancy-related care. Accordingly, *the Panel recommends that the leaders of EPSDT and Title V, at both the State and Federal levels, review and revise program policies and expenditures to ensure that adolescents are provided with an adequate portion of the total services administered by each program, that where possible a broad range of adolescent needs are addressed by such programs, and that Congress periodically review the extent to which the multiple health service needs of adolescents are included in program priorities.* In particular:

- EPSDT should increase outreach efforts to adolescents in such programs as Job Corps, where Medicaid-EPSDT eligible adolescents are likely to be found; ensure that the assessments performed on adolescents are developmentally appropriate; fund demonstration projects to develop ways to involve more adolescents in EPSDT; and widely disseminate the findings and techniques of successful demonstrations, especially to other EPSDT programs.
- State Title V agencies, with the encouragement and leadership of the Federal Government, should ensure that their needs assessments and State plans include specific attention to adolescents; increase their training programs to help improve the skills and competencies of service providers who care for adolescents; and review their direct service programs to ensure that adolescents are adequately represented and that adolescent services are not confined to pregnancy-related care only.

- The health planning systems at the State level in particular should assess the extent to which EPSDT, Title V, and other programs are giving adequate attention to adolescents.

Although the Panel believes that such changes in existing systems will do much to advance adolescent health, it is also true that to reach some teenagers, and to address some special problems, new systems may need to be established. For example, age-specific, comprehensive, multiservice centers have demonstrated their attractiveness to certain teenagers who might well remain totally without health services were it not for this type of care setting. Inner city youth, particularly those disaffected and alienated, may well use only such a model—to the exclusion of other systems, such as hospital-based clinics—no matter how much these systems try to reorient their programs and procedures to suit adolescents. To encourage the development and expansion of such comprehensive services to adolescents, *the Panel recommends that public and private funding sources increase their support of multiservice, single site systems of care for adolescents, undertake administrative changes to ease the pooling of funds typically drawn from several categorical sources, and develop common forms for reporting expenditures, program activities, and related factors. Such expanded support should include a strong evaluation component to refine understanding of the strengths and limitations of this model for serving adolescents.*

New systems of care are also needed to assist pregnant teenagers and teenaged parents with their multiple health, social, educational, and occupational challenges. The establishment of the Office of Adolescent Pregnancy Programs in DHHS symbolizes Federal recognition of this need, but, as we discuss in chapter 11, the placement of this program in the office of the Assistant Secretary for Health may have limited the benefit of this program. Even in communities where all needed services for such adolescents exist, only the most extraordinarily resourceful teenager can "package" them appropriately. Although there is no single way to ease this service coordination problem, which certainly includes the health system but goes well beyond it, *the Panel recommends that each community designate a lead agency to coordinate the broad array of services needed by pregnant adolescents and teenaged parents. Similarly, all those charged with maternal and child health planning at the State level should review the extent to which communities have met their responsibility.*

CHRONICALLY IMPAIRED CHILDREN

Over 10 million children in the United States suffer from some type of chronic impairment (*3, 4*). Although the majority of their medical needs are met satisfactorily, and often extremely well met, the fragmented nature of our health care delivery system continues to leave some serious issues untended and often places substantial burdens on the very people who can least sustain them. In particular, children with chronic disease, physical and sensory handicaps, mental retardation, and emotional disturbances (1) continue to find it difficult to obtain comprehensive health care, (2) often suffer severe financial privation, (3) are frequently ostracized or segregated from peers and society in general, and finally, (4) lack support when they must undergo trying personal and interpersonal stress. Large sums of money are spent each year at the Federal, State, and local level for services to the handicapped, yet serious organizational and delivery problems remain. A number of the problems arise from procedures and policies which should be reassessed and, in many cases, altered to improve the quality of life of children with handicaps or in chronic poor health.

This section begins with a delineation of issues specific to each of four groups of disabled children—those with chronic disease, those with physical and sensory disabilities, those with mental retardation and those with serious emotional disturbance. A discussion of the problems facing children who have multiple problems follows. The final two sections outline a number of general issues and provide specific recommendations addressing the problems for individual children and their families and for children with chronic illness and disability in general.

Children with Life Threatening or Chronic Diseases

It is difficult to obtain definite figures for the number of children in the United States with life-threatening and chronically disabling disorders. Estimates range as high as 3 million children (*5*). Whatever the precise figure, substantial numbers are involved and many of their lives are filled with suffering. Children with chronic disease may spend up to several weeks a year in the hospital, lose numerous days from school, face restrictions on their outside activities, and have to adjust their lives around rigid treatment regimens and schedules.

The composition of the chronically ill child population is changing. Although advances in prevention have virtually eradicated or significantly reduced some disorders (e.g., rheumatic heart disease, paralytic poliomyelitis, tuberculosis, and other infectious diseases), new diagnostic and therapeutic techniques have led to the recognition and management of a variety of diseases that previously caused death in infancy or early childhood. The result is an increased population of chronically ill children. A partial list of these "new" illnesses includes: some forms of congenital heart disease; dialysis-dependent renal diseases; many newly identified endocrine and metabolic disorders; certain immune disorders; various congenital and acquired neurological diseases; and treated malignancies.

Corollary to the changing nature of chronic disease is its changing age distribution. As therapy becomes more advanced and successful, more and more chronically ill children are living into adolescence. Hospitals are starting to see a shift in patient population with increasing numbers of beds used by chronically ill adolescents and young adults. Retraining of staff and rethinking of hospital policies are necessary in many instances. Furthermore, pediatricians, specialty clinics and general practitioners who continue to follow their chronically ill patients into adolescence are finding that the problems their patients confront them with often concern such nontraditional areas as sexuality, birth control and vocational placement.

The increased survival of chronically ill youngsters is a direct result of and tribute to the massive mobilization of support for the development of tertiary care centers over the past two decades, including construction of new facilities, training personnel, and designing new equipment. It is in this high-technology sector of medical care that children with life-threatening and chronic diseases typically receive their specialty services. What seems to be lacking at this time is the community backup supports for the less highly visible needs of these children. Unfortunately, the enthusiasm to provide specialized medical services to ill children has not been matched by proportionate dedication to other needs. The Panel perceives as gaps in the provision of services the following important community health supports: home health services, other alternatives to hospitalization, prevention and preventive maintenance (including primary and dental care), respite services and other family support services.

In general, most professionals dealing with chronically ill children agree that for the sake of the child, hospitalization should be kept to a minimum. The current costs of hospitalization make this an attractive economic notion as well. Many efficacious outpatient and home-based services have been developed, but these services are often not available to chronically ill children because third-party payments are not available. Consequently, physicians are forced to hospitalize children for diagnostic studies, blood transfusions, and total parenteral nutrition to spare parents the expense. It is ironic that expensive hospital bills will be paid by insurance plans while payment for cost-saving services such as outpatient and home care is required of families in out-of-pocket payments.

Youngsters with chronic disease are also often hospitalized bacause no other residence is available while they are receiving extensive treatment such as radiation or chemotherapy. Although these procedures may take only a few minutes a day, the child must often spend long hours in a hospital bed and a hospital environment. Every effort should be made to develop nearby homelike settings (or hospice centers) where children can be monitored, but spend a more normal day. Efforts in this direction are starting, particularly through private charitable organizations, and should be supported and expanded.

Children with chronic disease require primary care in addition to special services. For a variety of reasons this care may be lacking or not well coordinated with other aspects of their health program. Preventive health maintenance is often not covered by third-party payers, and some programs serving chronically ill children are not designed to include primary care. Much of the difficulty, however, stems from simple lack of communication among providers and between patients and providers. Parents often think that when a child sees "the doctor" he or she is getting comprehensive services. On the other hand, "the doctor" of the chronically ill child is often a specialist who may assume that the child is receiving primary care services elsewhere (*6*). Although this situation is not universal, it occurs frequently and can be ameliorated by clear specification of provider roles. As a system of care is planned, program designers should always consider the coordination of primary care needs of these children with their specialized needs. This becomes all the more important as the child returns to a more stable state and can be cared for by health care professionals in his or her community.

Another aspect of care that is sometimes overlooked for handicapped children is dental health. This subject is addressed in chapter 5. Finally, support services to help parents acquire the special knowledge they need about diets, medication, and financial resources are not always readily available.

Some programs funded through State Crippled Children's Services and the Bureau of Community Health Services have been designed to meet the comprehensive health care needs outlined above. Model programs for cystic fibrosis and hemophilia A and B have been successful in reducing hospitalizations, prolonging the life span, and improving the quality of life of children with these serious illnesses. However, because the pattern of Federal programming has been piecemeal and categorical, there are wide disparities in the types of health programs available to children with different chronic conditions. The Panel recommends that as modifications are made at the Federal, State, and local levels for chronically ill children, planners review the experience of model programs and adjust for needs such as home care, hospice placement, coordination of specialty and primary care, and provision of family supports.

The financial burden on families with chronically ill children is often a significant additional concern, with much of the cost being "hidden." Although the major health care bills for hospitalization, surgical procedures, medicines and the like may be covered by private insurance or by a public program, there may be heavy travel, telephone, and lodging costs that are never reimbursed. Furthermore, parents may lose weeks of work for which they cannot claim compensation. These costs may throw a family over the financial brink (*7*). The worst situation occurs, obviously, for the family without any source of third-party payment for whom hospital and clinic fees may represent clearly impossible expenses and stand as barriers to care.

In addition to other difficulties, children with chronic conditions may suffer from societal intolerance. This problem is being alleviated by new community arrangements for these children undertaken in response to Federal initiatives such as P.L. 94–142 (the Education for All Handicapped Children Act) and other legislation for the handicapped. The greater problem for children with chronic illness, however, may be their own self-acceptance, their relationships with peers, and the emotional stress which the uncertainty of their disease places on them and their families. Children with chronic disease are continually faced with the actuality or the prospect of pain and suffering, and with the fear of hospitalization, functional disability, and even death. These very real problems are, of course, exacerbated in adolescence as the youngsters begin to search for independence and group identity. Hampered by dependence on treatment and medicine and their own sense of being different, such children may find that growth and development comes only with real difficulty.

Children with Physical and Sensory Handicaps

A Rand Corporation report has estimated that 193,000 children in the United States are visually impaired, 490,000 hearing impaired, 2,200,000 speech impaired, 1,676,000 crippled or other health impaired, and 50,000 multiply handicapped (*3*). These numbers fit the estimate of others that "physically disabled" children constitute one-half to two percent of the childhood population. Physically disabled children share many of the problems of chronically ill children and the Panel feels they would benefit from a number of modifications in the programs designed for them.

These children need coordinated health care and help with life planning. Unless problems are recognized early and intervention begun, the child's performance and ability to learn and develop may be adversely affected. If there is a hearing problem, there may be a delay in speech; if there is a vision problem, there may be a problem with intellectual development; if there is a speech difficulty, there may be a delay in social development.

In the past, many problems were not identified until children entered school. This was because many preschool youngsters received few developmental examinations between the completion of their immunizations and the time they began school, and because there was no way to identify, at birth or shortly thereafter, the children who were at risk for being disabled.

This situation has changed. The great majority of infants born at high risk now receive care in the high-risk nursery system that has been developed throughout the Nation, and studies have identified the criteria needed to recognize those high-risk infants likely to have developmental problems. Thus, for the first time, children with physical and sensory deficits can be identified at a very early age and intervention programs can be promptly initiated.

Because many physical and sensory handicaps interfere with a child's overall ability to function at home and at school, current theory suggests that the best approach to management is through collaboration between the family and a community team of physicians, nurses, educators, physical therapists, occupational therapists, speech and hearing personnel, nutritionists, and psychologists. In practice, three serious roadblocks hamper the smooth operation of these teams. First, evaluation personnel (particularly those in academic centers) often operate in a vacuum with little reference to the child's actual home and school setting. This is a difficult problem because the concentration of professional expertise to create a team often requires that the evaluation take place in a center (usually in a city) where team members may know very little about the resources actually available to the child in his or her own community. The creation of community teams would ameliorate many of the coordination problems and allow closer connection between evaluation and treatment. The large centers could still serve a major consultative and training function and could, in fact, function as the community team for their immediate area.

A second difficulty is that leadership of the evaluation team is often lacking and even though proper tests have been carried out, coordination and follow-through are often left in the air. This absence of leadership is particularly marked when the child has a variety of physical and functional problems. A major need for an ombudsman or advocate is evident and many feel that pediatricians and other primary care providers should be prepared to fill this void for physically handicapped children (*8*). Although most primary care providers have neither the training, resources, nor time to handle all the complex problems of physically handicapped children, they can become active members of a community team, availing themselves and their patients of advanced diagnostic and treatment programs as well as the services of a variety of other professionals including, for example, occupational therapists, physical therapists, and speech and hearing specialists. Within the team framework the primary care provider can maintain an active role as advocate, interpreter, and coordinator.

In order to learn how to function in a team and to fulfill the coordinator role competently, pediatricians, family practitioners, and nurses may need continued training and updating. This training should contain information about resources with particular emphasis on programs for handicapped children available through the schools under P.L. 94–142 as well as through other public agencies. The efforts which have begun in this regard by the American Academy of Pediatrics and Federal education authorities should continue.

One final problem currently interfering with the full and efficient use of teams is the increasing number of services tied to one or another individualized treatment plan. It is currently possible for a given child to undergo as many as five or six individualized evaluations with different teams in order for services to be provided under P.L. 94–142, the Early and Periodic Screening Diagnosis and Treatment program (EPSDT), Title XX, Developmental Disabilities, Crippled Children's Services, and the Disabled Children's program under Supplemental Security Income. Program regulations should be changed so that the same evaluation would satisfy all accounting and bureaucratic needs and so that all agencies involved with a handicapped child (e.g., school, hospital, mental health center) know which services the child is receiving. Although this might place a slightly heavier burden on the evaluators, it would spare the child and family multiple taxing and stressful procedures and would allow a truly comprehensive program to be developed for each child.

Just as there are hidden costs for the families of children with chronic disease, so are there for the physically handicapped. If a child is in a wheelchair, the corridors of his or her home may have to be widened. If he or she needs braces, the parents may have to pay out of pocket for the equipment and then bill their insurance company—only to find that many such expenses are not actually covered. A child with a hearing aid may require multiple visits for adjustment, each meaning loss of work time for a parent as well as transportation and other costs. Although a wealthy family may be able to absorb these expenses readily, others cannot.

The psychological problems of physically disabled children often stem from their conscious and unconscious realization that they cannot perform as other children do. Just as chronically ill children require ongoing mental health support, physically handicapped children often need buoying and encouragment to get them through the exceedingly difficult task of growing up.

Major improvements in the health care and the everyday experiences of physically handicapped individuals have come about in the past two decades. The Panel feels that it is essential that the good work that has begun continue and that every effort be made to coordinate activities for these children at the community level.

Children with Mental Retardation

Two to three million children in the United States are considered to be mentally retarded. Definitions of retardation vary depending upon the source consulted, but the major issue for the children is that they require specialized training and monitoring because of cognitive and adaptive deficits.

The etiology of some retardation can be traced to metabolic, genetic, or traumatic factors. Certain brain infections and toxins cause additional cases of severe and permanent cognitive impairment. Explanations such as these account for approximately 250,000 to 350,000 mentally retarded youngsters under the age of 18, and tend to be diagnosed early. Because of the organic conditions which accompany these types of retardation, morbidity and mortality for this group is significantly higher than average.

A second group of youngsters suffer from mental retardation due to psychosocial disadvantage. In contrast to the children with clinical retardation, their cognitive disability tends to be primarily in the mild range and is generally so labelled only after they enter school. Because such a large percentage of these children have histories of significant financial and social deprivation, it is clear that poverty, disadvantage, poor nutrition, and environmental hazards play a major role in the causation of this type of retardation. Such children do not tend to suffer from increased morbidity and mortality.

Major progress has been achieved in the prevention and minimization of mental retardation through advances in genetic screening and prenatal diagnosis; care of prematurely born infants; screening, diagnosis, and treatment of such disorders as phenylketonuria, galactosemia, and hypothyroidism; reduced incidence of measles and rubella; and an improved understanding of the effects of toxins such as lead and alcohol, and of the importance of early stimulation. The national network of 12 Mental Retardation Research Centers established by P.L. 88–164 and operating under the leadership of the National Institute of Child Health and Human Development has been one major force contributing to such progress, and such research programs focused specifically on mental retardation should be continued and expanded to maintain the momentum now evident. The university affiliated programs administered by the Office of Maternal and Child Health in DHHS are another major source of tertiary care services, community consultation, professional interdisciplinary training, and research into the problems of this population.

As health care providers continue to emphasize prevention, recognition is needed that the current health care system is inadequate for youngsters with mental retardation in a number of respects. In addition to the problems of coordinating primary and specialty care, which are similar to those outlined for children with chronic illness, there are four areas of gross shortage in health services for retarded children. These are medical coverage for children in 24-hour residential placement, the care of superimposed handicaps, mental health care, and dental care.

Severely retarded children are often placed out of their homes with no access to their family health care provider. As a result, it is the responsibility of the agency caring for the child to provide adequate health care. In the past, most such children were placed in large institutions that were often managed by medical authorities. However, health care in these institutions was seldom a high priority and often little more than crisis care was provided. With increased public awareness of retarded citizens, new systems of primary health care are being established in large institutions with some measurable success. At the same time there has been a growing recognition that institutionalization aggravates existing retardation by divorcing children from normal experiences, stimuli, and relationships. As a result, when out-of-home placement has been required, it has increasingly been arranged in small community-based group care facilities. As beneficial as this change should be, there is considerable variability in the health care available to children in community group homes. All too often, only spotty medical and other support services have been available to children dispersed into the community.

Children with mental retardation share with physically handicapped youngsters the need for a team approach to their complex problems. Because so many youngsters are now returning to communities, the desirability of community teams trained in the evaluation and followup of children with retardation and associated problems is underscored. A major area of need for retarded children is apparent in mental health, an issue addressed in chapter 5.

Maternal and child health authorities have recognized the importance of dental health for the retarded population and for the past 20 years have supported relevant pedodontic training. Furthermore, the Robert Wood Johnson Foundation's model program in dental education for the care of handicapped individuals has made an impressive impact on the dental care of retarded persons (*9*). Nonetheless, dental care is still needed by many mentally retarded children, and extension and expansion of dental services to this group should be given attention in dental health planning.

The families of mentally retarded children have substantial needs that the current health care system addresses only marginally and certainly not systematically. Increasing evidence indicates early identification and acknowledgment of a child's retardation necessitates a supportive network for parents, and that effective intervention is facilitated if families are included in the planning and implementation of services. Early intervention and family support systems should be buoyed at all levels. There is an opportunity for expansion of early identification and intervention programs through or in collaboration with P.L. 94–142, that includes the specific goal of providing educational and related services to all handicapped children from birth.

Family supports in terms of jobs, housing, and food should continue to be a major concern of program planners for this group as well as other special-needs children. The double indemnity of poverty and retardation should be recognized when children with mental retardation are born into poor families. In addition, respite care should be readily available to parents who become the 24-hour-a-day caregivers for their retarded children. Parents and siblings often need a rest from such high intensity demands.

At different times, mental health, public health, special disability councils, and education have been given the major responsibility for setting priority and policy for retarded citizens. Even when a single group has been designated as responsible, there has been no clear delineation of the extent of that responsibility, with resultant overlapping mandates, conflicting procedural guidelines and in some cases contradictory philosophies. Under the Developmental Disabilities legislation, for instance, a statewide council is responsible for setting policy, but the council has limited financial resources and cannot actually carry out many of the policies it recommends. As a result, other agencies, whose own policies may be quite different, may have to execute two or more mandates. At present, this situation is particularly pressing with regard to the criteria established to determine if children are eligible for various programs.

The Federal Developmental Disabilities legislation is being construed too narrowly to meet the needs of many mentally retarded children. This legislation was intended to provide "comprehensive services," in addition to special services, for a group of individuals suffering from chronic disabilities whose needs spanned several human service fields such as health, education, social welfare, and rehabilitation. The original act included, among the developmental disabilities, other specified clinical diagnostic groups such as cerebral palsy and epilepsy. Recent amendments discarded this diagnostic approach and defined developmental disability as a severe chronic disability which: (a) is attributable to a mental or physical impairment or a combination of the two; (b) is manifested by the age of 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of seven specified life activities; and (e) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services.

It is highly probable that most mildly mentally retarded individuals will not be considered "developmentally disabled" and thus will not be eligible for services as a result of these amendments, even though other program rubrics (for instance those of P.L. 94–142) definitely would make them eligible. In at least one State, occupational and physical therapy resources available through the Crippled Children's program to the whole range of retarded and disabled youngsters are threatened with restriction to those children who were most severely functionally impaired. It would seem that the overlapping and contradictory procedural guidelines have the potential for affecting large numbers of children. Under the current Developmental Disabilities Act definitions as many as 2 to 2.25 million children could be reclassified as ineligible for needed services.

Severely Emotionally Disturbed Children

It is difficult to get an accurate and comprehensive picture of the extent of serious emotional disorders among children in this country, but it is clear that a large number of young people are in serious trouble and need competent professional assistance. Federal education authorities report some 1.5 million emotionally disturbed children are receiving special education services in the schools, and Rand Corporation figures indicate a total of 2 million children per year receive a variety of public and private services (*3, 5*).

Emotionally disturbed children come from all socioeconomic classes and can be found in a range of settings, including correctional facilities, programs operated by welfare and social service departments, private and public residential treatment centers, and in the community in their own family homes.

The number of children with mental health problems, and the severity of those problems, seems to be increasing. Adolescents, for example, constitute the fastest growing admissions category in psychiatric hospitals. Suicide and homicide rates among both children and adolescents are increasing at an alarming pace, and growing numbers of young people display learning disabilities, and problems with drug and alcohol abuse.

The dominant paradigm for treatment of emotional disturbance and mental illness in children and youth is psychotherapy in conjunction with medication, generally in a therapeutic milieu. This treatment mode requires the skills of psychiatrists, clinical psychologists, psychiatric social workers, and psychiatric nurses—highly trained specialists whose services are expensive. Further, this type of treatment tends to be quite prolonged, which adds to the costs. For families with limited resources, the expense may constitute an insurmountable access barrier—especially because insurance coverage for such treatment is often limited.

Equally troubling is the fact that although traditional treatment approaches are highly effective with some individuals, they do not work very well with (1) children and youth from educationally disadvantaged environments where verbal communication is inefficiently used in problem solving; (2) those whose socialization varies sharply from mainstream expectations; and (3) those from families and neighborhoods so disorganized that the normal sources of affection, support, and discipline needed to sustain therapeutic efforts are lacking. Children in these three categories constitute a substantial proportion of the emotionally disturbed group, but their needs are not being met and some mental health specialists are actually trying to redefine the problem in a way that will exclude such children. A number of residential treatment centers already refuse to accept them, limiting admission to children who are depressed, suicidal, neurotic, psychotic, or suffering from disorders, such as ulcerative colitis or anorexia nervosa, believed to have a high psychosomatic component.

An essential first step toward resolving some of these problems is to recognize that children in need of mental health services are found not only in psychiatric treatment centers, but also in the schools, the

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correctional system, the social service system, and the community. Mental health specialists must be prepared to assist emotionally disturbed children wherever they are, regardless of what service system has primary responsibility for their overall care (see chapter 7).

Second, the treatment approach itself must be reconceptualized to include more types of intervention. The mental health problems of children are inextricably bound up with the most basic problems of living, and cannot be "treated" apart from the family, neighborhood, school, and community, which are the normal socializing influences of society. Many emotionally disturbed children need common-sense assistance in relating appropriately to peers and adults, and can be helped by mental health counseling which differs from the traditional approach in that it is relatively nonverbal, and does not seek psychodynamic or etiologic roots. The emphasis is on current needs and current function, and upon strengthening both the natural support systems around the child and the youngster's ability to make use of those supports.

In this type of mental health intervention, the role of the psychiatrist or other highly skilled professional is to investigate the child's natural setting and devise a treatment program that takes advantage of the skills of parents, siblings, teachers, friends, case workers, counselors, and others to carry out the bulk of the therapy through day-to-day support, protection, discipline, and guidance. This "ecological" approach emphasizes treatment in as near to normal settings as possible, with an eye to restoring or creating an effectively functioning support network for the child and enabling him or her to respond appropriately to it. When children must be removed from normal settings, it should be for the least possible distance in time, space, and psychological effect.

To redirect the emphasis of mental health services for emotionally disturbed children to reach the full array of young people in need of help, new institutional arrangements need to be devised. Psychiatric professionals, for example, should assume major consultant and training functions. They will need to identify and help to train various personnel in the community—social workers, nurses, teachers, counselors, and so forth—who can work effectively with emotionally disturbed children. They will also need to provide backup for such "front-line" workers, especially in handling difficult and complex problems. Expanded programs for emotionally disturbed children and youth should seek to multiply the effectiveness of highly trained and expensive mental health specialists such as psychiatrists, clinical psychologists, and psychiatric social workers, and to make systematic use of the abundant pool of competent, concerned community personnel able to work effectively with many troubled young people.

Finally, with regard to mental health programming, a particularly difficult issue that needs urgent attention is the increasing suicide rate. Although part of the problem is the increasing stress on youngsters, another is the inadequate facilities for the care of youngsters who are suicidal. Suicidal inclination is acknowledged as a medical emergency and yet often there are not services available in appropriate settings to handle this crisis.

Children with Multiple Handicaps

Statistical accounts acknowledge about 50,000 children as multiply handicapped. However, when multiply handicapped refers to a child with both physical *and* emotional disturbance or both mental retardation *and* physical disturbance, the number increases. The health care system is designed to respond to single or primary problems, not to individual children who may have a variety of problems. Thus it often does not meet the needs of such children.

Parents of multiply handicapped children often find they must wend their way though a maze of different public and private programs in order to obtain the services they need. They must learn the eligibility criteria for each and find ways to justify their child's inclusion. The specificity issue is especially problematic in regard to mental health and retardation. Criteria are often such that a child may be both too "emotionally disturbed" for services provided to children with developmental disabilities and too "cognitively impaired" for mental health services. These children make up a substantial proportion of current residents in State schools. Often their histories reveal that their parents sought fruitlessly for services for years prior to admission. When services for children with multiple problems are provided, it is often only in a fragmented fashion. For instance, a child with Down's Syndrome and leukemia (a common association) may fit the criteria for Crippled Children's Services because of his chromosomal anomaly but not because of his cancer, and conversely may receive other services for his leukemia from a voluntary care program which is not designed to help with his Down's Syndrome. The integration is often left to parents rather than being provided as a necessary adjunct to health care.

Common Themes

Certain general themes emerged from the Panel's review of the health care needs of children with chronic illness and handicaps. First, coordination of care with elimination of duplication and unnecessary categorical restrictions is urgently needed. Second, professionals at all levels need more training to deal more effectively with these children. Third, prevention and early identification efforts need support and expansion. And fourth, the families of such children need significantly more financial and psychosocial support.

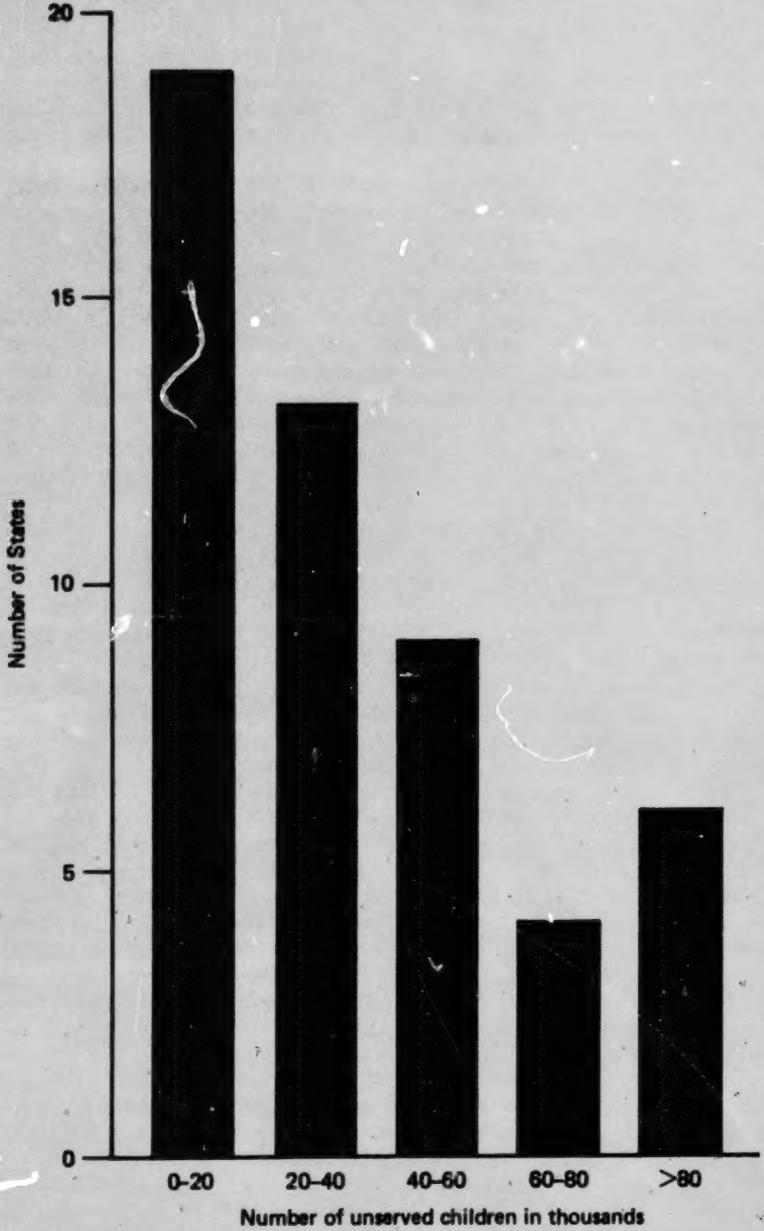
Until fairly recently, Federal policy toward chronically impaired children was concentrated largely in the Crippled Children's component of Title V and in programs for the mentally retarded and severely disturbed. Since the 1960's, however, both the number of programs and their scope have increased, to the point where there are now seven major service programs spanning the health, education, and welfare sectors: the Title V Crippled Children's Services program; P.L. 94-142; Head Start; the Developmental Disabilities program; the Disabled Children's program under Supplemental Security Income; EPSDT; the Vocational Rehabilitation program; and a number of mental health programs. Each has its own target population, funding, regulations, and operational base. No single agency or authority at any level of government is responsible for identifying all children with chronic impairments, diagnosing their needs, and ensuring that comprehensive health services are provided them. Until there is an agreed upon Federal-State-community system to facilitate provision of coordinated services by a community team, these children and their families will continue to face problems and shortfalls in the services they receive.

The type of health services a chronically impaired child receives and the site at which they are provided depends to a large extent upon financial status. The poorest children tend to receive services in hospitals, often in an episodic and impersonal fashion with frequent changes in provider personnel. Children from families of modest means with no insurance coverage are more likely to receive care through the Crippled Children's Services program or maternal and child health service centers. And children whose parents are more affluent or have extensive insurance coverage are most likely to receive care from private physicians, often specialists. No one of these approaches or providers always insures that the child is receiving comprehensive health services—primary care as well as specialized services, preventive services as well as acute treatment, psychosocial services as well as medical care.

The Panel's investigation indicates that at the Federal, State, and local levels, a central authority is needed to assume major responsibility for the full coordination of various health-related programs for physically and mentally handicapped children, especially those supported wholly or in part by the above-mentioned Federal programs. Whenever possible a community team approach should be taken with every effort expended to complement school based efforts under P.L. 94–142. This coordination may be accomplished if health authorities are willing to help in the individual evaluation process, to share data with the school planning team, and to help in the provision of related services.

P.L. 94–142 has increased opportunities for handicapped children and through its related services provisions has brought a challenge to health providers to upgrade and extend services. This major legislation has also heightened awareness of the needs of handicapped children and made it clear how inadequate the training of most health providers is in combining knowledge of child development, functional ability, and handicapping conditions. Programs established to meet these training needs should be continued and expanded.

Another general Panel concern is that the promotion of child health must include prevention of handicaps and chronic impairment. As mentioned earlier in the report, many conditions discussed in this chapter are preventable by early detection and management (e.g., PKU, hypothyroidism), improved prenatal and perinatal care, immunizations, accident prevention, and improved social conditions. Likewise, early identification and intervention can do much to alleviate the secondary consequences of many conditions. Unfortunately, in many States such services are available only on an incomplete and fragmented basis through programs established by the Federal and State Governments, or through the private sector, requiring the family to be able to pay. Because results from these



Number of States with specified numbers of potentially unserved handicapped children under P.L. 94-142: United States, 1977-78 school year programs are beginning to be effective, the current situation where some handicapped children receive early intervention and others do not is clearly inequitable; all should now be assured access to such programs. Health authorities should take the lead in the early identification of handicapping conditions, especially in infants and young children 5 years old and under.

Recommendations

The health problems of all children described in this section are so serious that they affect every aspect of the children's lives. To have any impact on these problems, programs must address the needs of the child, of his family, and of his community. Therefore, the Panel's recommendations are directed at improving services for each of these needs.

The Panel recommends that certain basic principles underlie the provision of health services to all children with chronic illness, physical and sensory handicaps, mental retardation, and severe emotional disturbances:

- Routine care for all such children should be in the home or as near to a normal setting as possible, with emphasis upon restoring the functioning effectiveness of families as well as enabling the young person to respond to the normal sources of support, affection, instruction, and discipline. When children must be removed from normal settings, it should be for the least possible distance in time, in space, and in the psychological effect of the experience, and to a locale where adequate services are provided.
- For all children with chronic or life-threatening diseases, hospitals should design systems that maximize use of care in nearby, homelike settings, including hospice care when necessary, to minimize the time these children must spend in the hospital itself. Efforts in this direction should be promoted and expanded by private charitable organizations and public programs, and should be reflected in private and public third-party reimbursement policies.
- Primary health care services should be available to these youngsters as well as the more specialized care required for the management of their specific handicapping condition.
- Mental health services should be readily available for all chronically impaired children and their parents, through the provisions of the Community Mental Health Services Act and other sources of support, both private and public. As often as possible, mental health services for young people should be made available through the systems and in the settings where the youngsters may be found—health settings, schools, correctional facilities, social services, and others.
- Dental health programs and policies should incorporate adequate provision for the care to meet the special dental needs of all such children.

- Special consideration should be given to the developmental concerns of adolescents with chronic impairment or handicap, to ensure in both ambulatory and hospital settings that issues of self-image, dependency, sexuality, peer relationships, and life plans are being addressed.

The Panel recognizes the special burden and challenges borne by the parents and siblings of children with chronic illness and handicap. In an effort to alleviate their problems, the Panel recommends the following:

- The families of children with disabilities and serious illnesses should have ready access to a wide range of psychosocial support services.
- As more families care for the special needs of their youngsters at home, provisions for training and aid in care for such children should be made. This should include training about diets, medications, and financial resources. Support programs to provide such training should be readily available via public health and social service departments as well as private health care providers.
- The hidden costs of care for chronically impaired children, including transportation, home renovations, special equipment, and lost work time for parents, should be taken into account more adequately in all relevant public and private programs of support.
- Respite care should be readily accessible for parents who become the full time caregivers of their handicapped children.
- Special tax credits should be created for parents caring for handicapped children in the home.

The Panel believes that a number of adjustments are necessary at the community level to optimize the use of public funds and resources for the improvement of the lives of handicapped children. The Panel therefore also recommends:

- Full implementation of recommendations elsewhere in this report to enhance the availability and accessibility of prevention services.
- Categorical research programs pertaining to the determinants of specific illnesses, handicapping conditions, and mental retardation should be continued and expanded.
- Health authorities in each State should play a major role in early identification of handicapping conditions in infants and children aged 5 and under, in a manner which lends coherence and coordinates with—rather than duplicating or paralleling—early identification activities of the private sector and the schools. Early intervention programs should be expanded.
- Training in the understanding and management of children with chronic disabilities should take place on all fronts. Because primary health care providers should assume a more active advocacy role in the coordination of services for children with physical and functional problems, current efforts to train pediatricians and other health care providers to be more effective in this role should be expanded. In addition, the University Affiliated Training Programs designed to train developmental specialists should be continued as a model of interdisciplinary professional

education. Increased attention should be paid to the training and utilization of related professionals, paraprofessionals, and community members in the various aspects of care. Training programs for parents should be expanded, and programs designed to sensitize nonhandicapped children to the special needs of their disabled peers should be made universally available.

- The training programs designed for health and social service personnel who care for chronically ill and handicapped children should underscore the needs of families for psychosocial care, including counseling and related social services such as transportation, and help with day-to-day home management and financial needs.

Clearer guidelines and specifications are needed in a number of public programs for smoother operation and greater benefits to the children served.

- All agencies using the individual service plan format for the evaluation of handicapped children should coordinate their requirements so that one evaluation and one plan can satisfy the accounting and programmatic needs of all service sectors—including health, school, hospital, mental health care, et cetera. Whenever possible, lead agencies should be designated and school, health, and social service agencies should establish community teams to coordinate services.
- A clearer designation of a policymaking group for each State is necessary. The Panel feels that for mental retardation services, the Developmental Disabilities councils should have greater authority in community and State health planning. At the same time, the Panel feels that the Federal Developmental Disabilities legislation must be construed broadly to include children with all levels of developmental disabilities rather than only the severely mentally retarded. For health planning, Federal, State, and local maternal and child health authorities should assume major responsibility for the coordination of various programs for physically and mentally handicapped children supported wholly or in part by Federal funds under the Title V Crippled Children's Services program, Medicaid-EPSDT, the Developmental Disabilities program, the Disabled Children's program under Supplemental Security Income, Vocational Rehabilitation, and Mental Health programs. Coordination should be directed at creating and maintaining a community team approach to health and health-related services, and a clearly specified system of backup medical services, for every handicapped child. The efforts of maternal and child health authorities in this regard should complement school-based efforts under P.L. 94–142. (See the Panel's specific program recommendations in volume II (*10*).)
- Whereas categorical services for the mentally retarded must be continued, State maternal and child health authorities should give technical assistance for health-related aspects of programs for the mentally retarded.

CHILDREN IN INSTITUTIONS AND FOSTER CARE

A substantial number of children are removed from their homes each year and placed in various institutions or foster care settings. Most of these youngsters are the responsibility of the juvenile justice system, the social welfare system, or both.

Although parents may voluntarily place their children in foster care because of a family crisis of some sort or an inability to meet the special needs of a child with a handicapping condition, many placements in institutions or foster care are involuntary and the result of court orders. Juvenile and family courts have traditionally had jurisdiction over three main categories of children: abused and neglected children found by the court to be receiving inadequate care and protection; juvenile delinquents, i.e., criminal offenders; and status offenders, that is juveniles who have not committed a crime but are beyond the control of their parents, are runaways, truants, or engaged in other forms of socially undesirable behavior. All of these children have health needs that must be addressed by those responsible for their care. In many cases, these needs are not being adequately met at present.

Juveniles in Confinement

Thousands of juveniles are confined each year in secure facilities, either in short-term detention facilities prior to court proceedings or for longer durations in juvenile correction facilities following court action. According to a U.S. Census Bureau survey, more than 500,000 juveniles were admitted to public detention and correctional facilities in 1979 alone (*11*). An unknown number spent at least some time in adult jails.

The vast majority of confined juveniles are classified as delinquent. Most are adolescents, and males far outnumber females. Because these youngsters are in effect wards of the State, the juvenile justice system in general, and the facilities where they are confined in particular, have a duty to provide them with adequate health care.

Physical Health Problems

For a variety of reasons, a high proportion of juveniles placed in secure settings suffer from health problems. Medical problems were diagnosed in 46 percent of the 47,288 adolescents examined over an 11-year period in New York City's single youth detention facility, to cite one case study (*11*). Confined juveniles are disproportionately from low-income families and minorities, groups that typically have more health problems than other persons. In addition, they share the growth and development problems of all adolescents, and may suffer from special problems such as alcohol and drug abuse, venereal disease, and untimely pregnancy related to the conduct that first brought them into the juvenile justice system.

Finally, confinement may exacerbate preexisting health problems or contribute to new ones. Juveniles may suffer injuries as a result of fights or self-mutilation. Staff attempts to "control" youngsters through handcuffs

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and other restraints, or through excessive medication, can also lead to health problems, as can the various forms of physical and psychological abuse that are all too common in many detention and correctional facilities.

Mental Health Problems

Although a paucity of data on the subject exists, most authorities believe the incidence of mental illness, emotional disturbance, and mental retardation is higher among confined juveniles than among those in the general population. The precise nature of the link, if any, between such problems and a youngster's involvement with the juvenile justice system remains unclear, although the issue clearly deserves further research attention.

There are fundamental questions about the appropriateness of placing youngsters with mental health problems in facilities that by and large lack the capacity to respond effectively to their problems. Juveniles who are mentally ill, emotionally disturbed, or mentally retarded all too often wind up in detention and correctional facilities without having their problems identified or diagnosed anywhere along the way. In other instances such youngsters are placed in confinement precisely beause there are no alternative facilities available.

Even with flexible and diverse alternatives, which a number of States are increasingly working to develop, there will continue to be some mentally ill, emotionally disturbed, or mentally retarded youthful offenders who must be placed in secure settings. Detention and correctional facilities have a responsibility to meet the mental health needs of such juveniles, just as they must meet the physical health needs of all those in their care. *Juvenile offenders with mental health or mental retardation problems should not be placed in secure detention or correctional settings that lack services to meet their special needs.*

A top priority for all detention and correctional facilities in which juveniles are placed is the prevention of suicides, which are more likely to occur among confined youngsters than among those in the community. Because studies indicate most suicides occur within 24 hours of admission, close observation of newly admitted juveniles is crucial. *All facilities should include adequate programs of suicide prevention, and should offer a full range of other preventive mental and physical health care.*

Needed Services

There are widespread deficiencies in the health care provided by juvenile detention and correctional facilities, many of which do not even have admission screening. Such screening is essential to identify seriously ill juveniles who should be transferred to hospitals or clinics rather than admitted, to diagnose health problems that will require immediate or continuing treatment, and to identify juveniles with communicable diseases. Beyond the preliminary admission screening, confined juveniles also need complete medical evaluations and appropriate treatment plans where indicated. *The Panel recommends that detention and correctional* *facilities provide a full medical evaluation to all juveniles on entry and periodically thereafter, and ensure ready access to primary health and emergency health care.* Many facilities cannot presently provide emergency care on a 24-hour basis, an important service. Regular sick call conducted by a physician or other qualified health professional, continuing clinical and supportive services, and infirmary or hospital care are also necessary for appropriate health care of confined juveniles.

Bad as many juvenile facilities are in providing appropriate health care to the young people confined in them, they are—as a group—far better than adult jails, where a substantial number of children are detained at least briefly each year. Only a tiny fraction of jails provide medical screening upon admission; indeed, studies have shown most either lack any medical facilities or have no more than first aid kits (*12*). Children in adult jails are under severe psychological stress and are too often subjected to physical abuse as well. The Panel joins other groups in urging that *Federal, State and local governments move to prohibit absolutely the confinement of juveniles in adult jails, and take immediate steps—until that objective can be fulfilled—to provide maximum protection to children held in such jails, along with comprehensive medical and educational services.*

Personnel

Services in juvenile detention and correctional facilities may be delivered on the premises by full- or part-time employees, off the premises by health care professionals working under purchase-of-service contracts, or by a combination of both. The choice of a delivery arrangement will depend upon the size and financial resources of the facility and the level of health care to be provided. Even large facilities with fairly comprehensive services need linkages with hospitals and medical centers in the community to meet complex or intensive care needs of their confined juveniles. All facilities, moreover, need to coordinate with community health services to assure continuity of health care after a juvenile is released. In the absence of adequate referral and followup mechanisms, a youth's health problem may actually worsen after release and his or her ability to function in the community may be impaired.

Whatever the service delivery pattern, *every detention and correctional facility should designate a qualified health professional or agency as the health authority responsible for arranging for all levels of care for that facility's juvenile population. This health authority should be routinely accountable to State maternal and child health authorities for the scope and quality of services.*

A major key to the quality of health care in secure settings lies in the ability of the institution to attract and keep high caliber professionals, an often challenging task. The practice of medicine in such facilities requires special sensitivity and skills, both in dealing with juvenile patients and in maintaining good relationships with other facility staff. Confined juveniles may be suspicious of or hostile to health care personnel whom they have not freely chosen and who may be perceived as just another part of the custodial staff. Such youngsters may sometimes fake medical complaints and otherwise try to manipulate health professionals for their own nonmedical purposes. Tensions can arise between health personnel and other staff regarding security precautions. Health personnel cannot be exempt from such security considerations, but they must nonetheless retain autonomy with respect to medical judgments and treatments.

Juveniles in Foster Care

The State is responsible for seeing that health needs of juveniles in out-of-home settings, such as foster families, group homes, and residential treatment centers, are adequately met. There have been few systematic efforts to identify and analyze either the health needs of children in foster care or in the availability and adequacy of services to meet such needs. *Research along these lines should be given high priority by appropriate agencies of DHHS.*

What little is known about the health status of children in foster care suggests they have a number of problems. One study, a 1973–74 evaluation of the physical, mental, and dental health status of more than 600 children in foster care in New York City, found that more than one-half had at least one chronic physical problem and 20 percent exhibited multiple disabilities (*13*).

Many children in foster care do not receive adequate health assessments and diagnostic services, despite the fact that regular health assessments are particularly important for children in foster care. There should be special, in-depth attention for foster children who have had multiple placements or have been the subjects of abuse.

Assuring continuity of care for foster children poses special problems because medical records may be incomplete as a result of poor tracking systems, or because children enter foster care on an emergency basis and there is little medical history available. Foster parents often lack information about a child's health needs, and records of past immunizations and medications may not be transmitted from one placement to the next. *The Panel recommends that DHHS, in developing regulations to implement P.L. 96–272, the Adoption Assistance and Child Welfare Act of 1980, require that care plans for children in foster care include a statement of the child's health needs, the health services being provided, and the agencies or individuals responsible for providing needed services.*

Children in foster care often receive inadequate treatment services as well as inadequate health assessment and diagnostic services. Although basic medical care for those in publicly supported foster care is covered by Medicaid in a majority of States, reimbursement for emergency care, orthodontia, and prosthetic devices is likely to be left to local option or to special State payments based on individual determinations.

Further, many handicapped children now in institutions could be placed in foster family homes if special support services were available, such as physical therapy, psychotherapy, mental health counseling, and training for foster parents to meet the child's particular needs at home. *The Panel recommends that foster parents willing to care for a handicapped or chronically ill child receive a higher basic support* *payment and that Medicaid reimbursement be extended to all physical and mental health services needed by children in foster care, whether those children are handicapped or not.* Demonstrations should be undertaken to test the feasibility of utilizing Medicaid-financed home health care to help some seriously handicapped children now in institutions to reside in less restrictive settings.

Until recently, children in foster care receiving public support payments and Medicaid lost their eligibility for such assistance if adopted by families with incomes over the eligibility cutoff for those programs. This created a severe financial disincentive for adoption of children with handicapping conditions because their medical care—in the absence of public funding—would constitute a significant financial burden for adoptive families. The Panel commends Congress for addressing such problems in P.L. 96–272, the Adoption Assistance and Child Welfare Act of 1980, and urges that regulations implementing this Act be designed to maximize prospects for adoption of children in foster care.

Children in foster care are already eligible for health assistance under a number of Federal programs. They may have case plans developed for them under P.L. 94–142, the Developmental Disabilities Act, the Social Security Insurance Disabled Children's program, the Title IV–B Child Welfare Services program, and the AFDC-Foster Care program. There is, however, little coordination among these nor any assurance that an individual child in foster care will receive the attention and benefits due him or her.

The Panel recommends that outreach efforts be conducted under State EPSDT programs and under P.L. 94–142 to contact foster parents and institutions to apprise them of the programs and assist children in obtaining needed services for which they are eligible.

ACCESS PROBLEMS OF SELECTED GROUPS

A combination of factors relating to language, culture, and geographic mobility create distinctive access problems for three groups of mothers and children—migrant and seasonal farm workers, Native Americans, and refugee and illegal immigrant families. The problems of each group pose a unique challenge to those responsible for the effective organization of health services; no single solution can be applied to all.

Migrants and Farm Workers

The Department of Health and Human Services estimates there are at least 800,000 workers and family members in the migrant population, and as many as 3,000,000 seasonal farm workers and family members. Most live in marginal economic circumstances that are, if anything, getting worse rather than better as a result of reduced job opportunities, inflation in living costs, and cutbacks in medical aid programs. Such individuals typically have little if any coverage under "mainstream" social welfare programs such as unemployment insurance, workers' compensation, Medicaid, and the like.

The Federal Government has a number of programs aimed at addressing the needs of migrants and farm workers, but these categorical programs have not always been adequately coordinated with each other. For example, the Migrant Student Record Transfer System sponsored by the Migrant Education program maintains records on approximately 600,000 students. In recent years, this system has been linked with migrant health service programs so that selected health information is included with a child's student record and moves with him or her as the child changes location. *This linkage should be extended to cover migrant children in Head Start, in health programs not presently included, and, if possible, in such additional Federal programs as the Supplemental Food Program for Women, Infants, and Children.* Thus, a child's student record would include not only selected health data such as immunization status, but also such data as his or her participation in Head Start, the Crippled Children's Services program of Title V, or the nutritional programs of WIC.

Maternal and child health plans developed by the States under Title V should contain explicit provision for meeting migrant health care needs. In States such as California, Texas, and Florida which serve as "home base" for thousands of migrants during a major part of each year, more aggressive Federal and State efforts should be undertaken to provide needed preventive and treatment services to mothers and children while they are in residence.

Federal efforts to assist migrant children would be strengthened by greater interagency cooperation, and could benefit from a series of cooperative projects utilizing DHHS as a lead agency but involving other relevant departments as well. These include the Deparments of Agriculture, Education, Housing and Urban Development, Labor, and the Environmental Protection Agency.

Native American Children and Mothers

Approximately 753,000 Indians and Alaska Native persons live on or near Federal reservations, more than one-half of whom are children and youth under the age of 19. The past quarter century has seen major gains in the health status and access to care of Native American children and pregnant women, largely through the efforts of the Indian Health Service (IHS), an arm of the Public Health Service of DHHS. Infant mortality rates, nearly double those of the rest of the population in 1954, are now virtually the same as the national average. Maternal deaths in childbirth have gone down 91 percent, and tuberculosis death rates have decreased 89 percent (*14*). Such improvements, obtained through an aggressive expansion of hospitals and clinics both on the reservation and in urban areas, are comparable to those enjoyed several decades earlier by the general population.

Native Americans in general, and pregnant women and children in particular, now suffer from many of the life style-related health problems that plague the rest of the population. These include: (*15*)

- Accidents: The age-specific accident mortality rate of Indian children 1–4 years old is about two-and-one-half times the rate for non-Indian preschoolers.
- Teenage pregnancy rates for Native Americans exceed those of the general population, and only 23.4 percent of all women of childbearing age are using contraceptives.
- Nutritional problems: Obesity is a serious problem among Native Americans—as it is throughout our society—and often has its onset in childhood.
- Alcohol abuse: There is some indication that fetal alcohol syndrome may be more prevalent among Indians than among other population groups.
- Emotional and behavioral problems: Two-thirds of the parents interviewed in one Indian Health Service survey have voiced concerns about their children's behavior. At present, mental health services for children are scarce because few if any IHS staff members are trained to provide such services.
- Child abuse and neglect: Although the data are incomplete, there is some evidence that the incidence of child abuse and neglect may be greater on reservations than elsewhere in society.
- Handicapping conditions: An estimated 10 percent of Native American children have handicapping conditions that require special services.

The Panel recommends that, in the 1980's, the IHS focus greater attention on these and similar psychological, social, and behavioral problems while continuing to address more traditional problems such as infant mortality and infectious disease.

The IHS provides direct health services to Native Americans through 50 hospitals and hundreds of health centers and clinics. The program includes preventive services such as sanitation, dental care, public health nursing, health education, nutrition, eye care, mental health services, alcoholism programs, and social services. *The Panel urges that Congress provide the support needed to sustain and expand existing IHS programs, and to initiate additional services in the areas identified above.* More needs to be done to ensure that increased numbers of Native Americans enter the health professions, that more team care involving physicians, dentists, mental health workers, and other professionals is made available, that water and sanitation services are expanded, and that primary care for urban Indians is increased and expanded. This requires ample support and vigorous implementation of P.L. 93–638, the Indian Self-Determination and Education Assistance Act and P.L. 94–437, the Indian Health Care Improvement Act.

The Health Care Financing Administration and PHS and IHS should also strengthen working relationships to reimburse IHS hospitals and their satellite facilities for care provided to Native Americans who are medically eligible. In addition, HCFA and IHS should develop innovative outreach practices such as the use of tribal councils to reach families and encourage them to obtain needed preventive health care under EPSDT.

Refugees, "Entrants," and Illegal Immigrants

Although all of these groups share some common problems in obtaining access to health service—including language barriers and cultural differences—they are treated quite differently by law and public policy. Refugees fare best and illegal immigrant families worst; the latter far outnumber the former by all available estimates.

Approximately 300,000 people, most of them Indochinese and Cubans, are currently eligible for benefits under the Refugee Act of 1980, which specifies that States shall be reimbursed for providing comprehensive services—including child health and welfare services—to refugees for 3 years after their entry into the United States. Unaccompanied children are entitled to services until age 18, or for at least 3 years, whichever is longer.

The health status of refugees is often poor at the time of their arrival in this country, but their problems tend to be remediable ones such as undernourishment and parasitosis. The Public Health Service's Office of Refugee Affairs supervises the provision of health care to refugee groups and seeks to assure that the scope of services is adequate. In general, the program has succeeded in providing refugee children with basic preventive care such as immunizations and in linking them with a regular source of primary care.

The principal problem with the existing law as it affects the health status and access to services of refugee children is the discontinuity that is built in by the 3-year eligibility limit or cutoff at the child's 18th birthday. *The Panel recommends that PHS's Office of Refugee Affairs assess this problem in detail, with particular attention to the difficulty of obtaining Medicaid eligibility for those children and families who remain poor after the initial entry period.*

The legal category of "entrants" has been recently created to describe those foreign nationals who arrive in the United States seeking political asylum or a better economic life who are not deemed to meet the legal qualifications for refugee status. Pregnant women and children who are classified as "entrants" are at a considerable disadvantage, because they are not eligible for benefits under the Refugee Act of 1980. In many instances, this means they immediately join the ranks of the medically indigent, receiving care that is far from adequate for their needs but is nonetheless costly to local providers.

Federal policy towards "entrants" is still evolving. DHHS has taken one positive step in deciding that unaccompanied "entrant" children should be eligible for the same comprehensive services as refugee children. The Department of State has made funds available for this purpose under the Migration and Refugee Assistance Act of 1962. *The Panel believes that no distinction should persist between refugees and "entrants" in determining the eligibility for health care of pregnant women and children.* Either the Refugee Act of 1980 should be amended to eliminate the distinction which now exists, or DHHS and the State Department should extend to all "entrant" children and pregnant women the arrangements now in use for unaccompanied children.

In addition to refugees and "entrants," thousands of children enter the United States each year as members of illegal immigrant families. Thousands more are born here to parents who are illegal immigrants. In either instance, the illegal status of the parents bars them from eligibility for Medicaid and hence makes access to health services more difficult for such families than for other low-income families. Such families typically have greater health problems, receive less preventive care and wait longer to see a physician than other people. They most often obtain medical care from hospitals, as indigents. The cost to hospitals in areas with a significant concentration of illegal immigrant families can be quite high. According to one study, care for such individuals in 1979 accounted for 3.3 to 6.4 percent of all patient costs in all hospitals in San Diego County, Calif. Approximately one-quarter of these costs were for pediatric and obstetrical-gynecological care (*16*).

Some have suggested that the easiest way to resolve such problems is to make illegal immigrants eligible for Medicaid. There are major problems with such an approach, however—including the prospect of increased Medicaid costs, the political question of whether it is desirable to extend free care to noncitizens and the likelihood that many undocumented persons would be reluctant to apply for benefits even if eligible, for fear of detection by immigration authorities. The Panel instead endorses and supports the policy of the Public Health Service permitting illegal immigrant families full access, with no questions asked, to comprehensive services available at Community Health Centers, Migrant Health Projects and Rural Health Centers. *In addition, Congress, DHHS and the States should develop means for providing more fiscal relief to communities where municipal health services provide care to significant numbers of illegal immigrant families.* And finally, the normal maternal and child health planning process under Title V in each State should reflect a concern for assuring health care access for such families.

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CHAPTER 9

FINANCING HEALTH SERVICES FOR CHILDREN AND PREGNANT WOMEN

The way in which health services are financed is the single most important determinant of how the health care system operates, what services are available, which professionals provide those services, and who will receive them. In the Panel's view, existing financing arrangements not only fail to enhance the Nation's efforts to improve the health of all Americans, including mothers and children—they often work at cross purposes to this objective.

The Panel found two fundamental problems with the existing financing of health care. First, public and private third-party payment systems as they now operate provide incentives that result in an allocation of physician time, distribution of physicians by specialty and location, and a manner of providing health services that collectively are unresponsive to a significant part of patient needs, especially those of children and pregnant women, and that unnecessarily drive up health care costs. Second, and equally important, current financing arrangements leave millions of Americans—an estimated 12.6 percent of the population—with no public or private health insurance protection whatsoever, and many millions more with coverage that is so grossly inadequate that insurmountable financial barriers to needed health care remain (*1*).

Fundamental changes are needed in the financing of health care for children and pregnant women to ensure that the basic goals discussed earlier in this report are realized. The most important of these goals is to ensure that all health and health-related services that the Panel has identified as needed be available and accessible to children and to pregnant women without regard to ability to pay.

Our recommendations for improvements in financing programs include proposals to modify the way that all third-party payers, public and private, pay for personal health services, steps that can be taken immediately to improve private insurance and Medicaid, longer-range national health financing proposals, and modifications to be made in grant programs both immediately and for the long run.

CHANGING THIRD-PARTY PAYMENT POLICIES AND PRACTICES

Our specific recommendations for changes in the way that third-party payers pay for personal health services reflect two major conclusions reached in the course of our deliberations about financial incentives and health care: first, that public policy should promote modifications and alternatives to existing methods of reimbursing health professionals and institutions, and second, that policies and practices of all third-party payers should be based on a more systematic assessment of the relationship between financing decisions and the availability, accessibility, appropriateness, quality, and cost of care.

Alternative Payment Methods

Under prevailing private and public third-party payment practices, hospitals are typically reimbursed for their costs (or sometimes charges) and physicians for the fees they charge for each service performed. The principal test employed by public and private insurers in setting reimbursement levels is whether costs, charges and fees are "reasonable" or "usual, customary and prevailing." As all of these measures are inherently relative, there is no incentive for any provider to reduce prices and every reason for them all, collectively, to perform more services and to raise their charges. The more "allowable" costs a hospital incurs, the more beds it fills, the greater its revenue. The more procedures a physician performs, the higher his income.

Economic motives are only one influence on the behavior and performance of health professionals and institutions. Incentives associated with peer approval, pride of workmanship and altruism often take precedence over the desire for financial gain or fear of penalties (*2*). Nonetheless, reimbursement incentives are unquestionably serving to drive health costs ever upward, without penalty or brake. Recognizing this, some third-party payers are assuming a more active role in deciding what services should be delivered, where, and by whom. Some Blue Cross–Blue Shield plans, for example, have moved to eliminate coverage of questionable or outdated procedures. The Health Care Financing Administration (HCFA), the Federal Government's third-party payment agency, now seeks professional guidance from the Public Health Service (PHS) on the efficacy and safety of some new medical procedures before making coverage decisions.

These and similar moves have been taken largely with an eye toward cost control. There is another problem with the current third-party payment system that is even more detrimental to primary care of all types, and particularly care for children and pregnant women, and that is the bias in prevailing third-party reimbursements that favors hospital-based, high-technology care provided by specialists. Services rendered in the hospital are more likely to be covered than those rendered in the physician's office. Physicians are paid more for the use of technologic procedures than for examining and talking with a patient, and more for

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the same procedure if they are specialists than if they are generalists. The disparity in reimbursement has been growing, not diminishing, in recent years. Between 1975 and 1978, reimbursements from Blue Shield of Washington, D.C. for the performance of technical procedures increased by more than 50 percent, although reimbursements for physician time with patients went up only 20 percent (*3*).

One result of this bias toward technology-oriented care is that physicians have been encouraged to master and utilize new and often valuable technologies and procedures, and hospitals have been encouraged to purchase and utilize innovative but often costly new equipment. However, current reimbursement biases adversely affect the income of primary care physicians, including those who serve children and pregnant women; discourage the provision of time-consuming services such as counseling which are central to disease prevention and health promotion; sometimes encourage hospitalization of patients, whether truly necessary or not; and disproportionately reward specialization on the part of providers.

Today, the options of those who need health care services and those who provide them are often severely curtailed by the coverage decisions and other policy determinations of third-party payers. For example, there are a number of services that many insurance plans will pay for only if the patient is hospitalized, even if those services can be provided safely, effectively, and far more economically on an outpatient basis. In other instances, services involved in the treatment of a disease may be fully covered but those that could prevent the very same disease are ineligible for payment. Or to cite a third common situation, third-party payers will reimburse physicians at a far higher rate for technology-intensive diagnosis and treatment approaches than for a "head and hands" approach to health problems. In theory, none of these payment policies dictates the decisions that physicians and their patients will make about the nature and location of health services provided. In practice, however, that is precisely the effect.

A number of respected researchers and health policy leaders have assessed the ramifications of the current reimbursement system and have described the problems arising from it. To cite but a few:

- The Task Force on Pediatric Education concluded the present system "discourages the time-consuming counseling essential in effective diagnosis and treatment of biosocial and developmental problems . . ." (*4*).
- The National Council on Health Planning and Development found that results of the current system include an "over-reliance on existing modalities originally designed for acute, inpatient care, for serving the chronically ill, and diagnosing the ambulant patient," as well as a "failure on the part of providers to consider the relationship between the costs of utilization decisions and the benefits that may be gained" (*5*).
- The Association of American Medical Colleges said the system discourages physicians from pursuing careers in primary care because present policies "pay a premium for diagnostic and therapeutic procedures and undervalue basic clinical knowledge

and skills." The AAMC report said: "Payment for the professional time invested in listening to, examining and counseling patients is so inadequate that generalists must keep their interval of time with each patient to a minimum and utilize it to order or perform procedures" (*6*).

- The Graduate Medical Education National Advisory Committee found the present system "favors the use of tests and procedures, rather than careful patient histories, physical examinations, patient education and counseling; favors hospitalization rather than ambulatory care; influences the future practice habits of physicians in training; discourages teaching in ambulatory settings; favors the selection of a site to practice in relatively more affluent areas or where satisfactory reimbursement levels are in place; and favors the perpetuation of present circumstances into the future and acts as a deterrent to change in present methods of health care delivery, e.g., makes it difficult for Medicaid patients to obtain private medical services and deters the use of nonphysician providers of health services. Indeed, it would appear that current reimbursement practices tend to contradict manpower policy objectives explicitly advanced in existing health professions legislation at the national level" (*7*).

Because current reimbursement practices and policies work against, rather than in support of, some of the health care objectives for children and pregnant women that we deem essential, the Panel recommends that *all purchasers of health insurance and all public and private third-party payers, in collaboration with health care providers, take steps to modify and create alternatives to prevailing methods of reimbursing health professionals and institutions, and to encourage their use. Such modifications and alternatives should include:*

- *Revision of payment schedules and methods to more adequately reflect the value of counseling and other time-intensive aspects of primary care and to decrease inappropriate incentives for performing technical procedures.*
- *Various methods of paying for packages of services, such as lump sum payments for specified services, annual or monthly retainer fees, and capitation payments and salaries for providers working in organized settings.*
- *Methods of reimbursement that offer equal incentives for training health professionals in ambulatory care and in-patient settings.*

The negotiation of fee schedules by third-party payers offers an opportunity for specifying the range of services that shall be covered and for seeking agreement on an appropriate fee for each. As experience with Medicaid suggests, however, it is important that fee levels be adequate to induce providers to offer such services.

There are a number of ways in which third-party payers can create incentives that will enhance the availability, accessibility and appropriate utilization of the services the Panel has identified as needed by children and pregnant women, including alterations in reimbursement levels for specific services to reflect more accurately the significance of each for the promotion and maintenance of health, and the time required to perform each service effectively.

A variety of payment methods that are alternatives to fees-for-service actually have double benefits: they serve the goal of cost control so important in the current inflationary era, and they may enhance the integration of health promotion and disease prevention activities with acute care. These payment methods include lump sum payments such as those made to obstetricians for prenatal, delivery and postnatal care; retainers to providers that cover a specified range of services for all patients who come to a physician for care over a period of time; capitation payments to cover all care needed by a fixed number of patients; and provider salaries, usually in organized settings, that do not vary according to the number of services provided.

The importance of modifying reimbursement practices to support the training of health professionals in ambulatory settings is discussed in the section of hospital outpatient departments in chapter 6 and specific proposals for developing better methods of reimbursement toward this end are outlined there. Although hospital OPD's are the most important single setting for training of health professionals in ambulatory care, similar issues of reimbursement to support training apply in other settings, including health departments, community health centers, and health maintenance organizations.

Toward a More Rational Basis for Payment Decisions

If such modifications are to be made, and the health care needs of all Americans—especially mothers and children—are to be more appropriately and adequately addressed in the future, then third-party payers, whether public or private, will need systematic expert guidance on which services are in fact needed, who is qualified to provide them, and under what circumstances or in what settings.

As we have discussed in chapter 5, the Panel recommends that a Board on Health Services Standards (or consortium of existing groups) be established to fulfill three functions: first, to review and continually refine our understanding of what health services should be available to mothers and children in light of new knowledge and changing health problems; second, to provide information and guidance to all third-party payers and others regarding the efficacy, effectiveness, and appropriate use of a given service or set of services, and the circumstances under which such services should be financed; and third, to provide information to all third-party payers and financers of health care regarding the likely effects of their payment policies and practices on the availability of needed services, professional personnel, facilities, and other components of the health care system. This third function is perhaps the most challenging of the board's duties. At present, our knowledge about, for example, the way that various coverage and reimbursement policies shape the quality of care is scant. Even those involved in health services research and evaluation do not typically go beyond *ad hoc* descriptive studies to systematic assessments of how payment practices might be altered to promote the availability, accessibility, and appropriate use of various types of health services.

The board envisioned by the Panel would attempt such comprehensive, systematic analysis, in addition to its other tasks, with the aim of providing information for use by third-party payers in designing their policies and practices; by States in the certification of private health insurance plans (discussed below); and by businesses, labor unions, and others who choose and/or pay for group insurance plans. Among the broad scale analyses that we envision the board undertaking we call special attention to two sets of reimbursement issues that should have a very high priority when the board or similar mechanism is established:

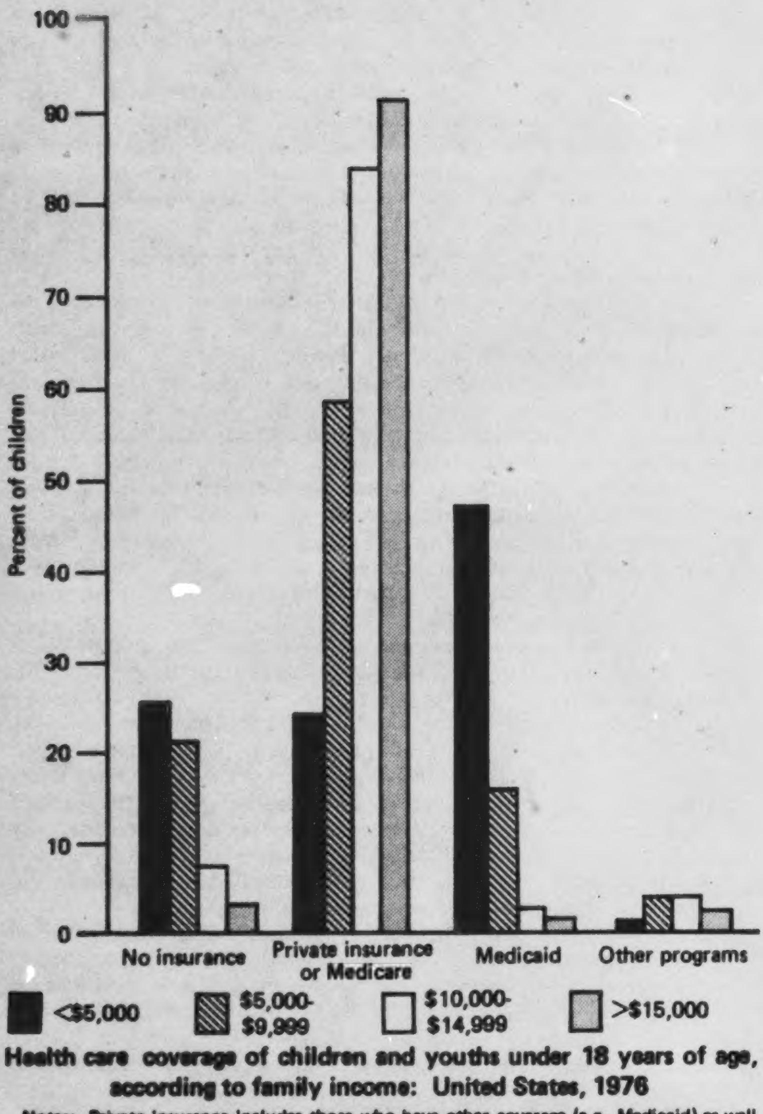
- What changes should be made in current reimbursement differentials to encourage the provision of health services to those most in need? Should third-party payers discontinue geographic differentials based on usual and customary fees that go beyond the differential costs of delivering services? Should third-party payers consider establishing higher payment levels for the provision of primary care services in underserved areas?
- Can services, functions and quality of care be defined with enough precision to allow reimbursement for a given service to be the same, regardless of who provides that service, as long as the provider meets certain standards and qualifications? Should reimbursement be made at the level appropriate for the provider who possesses the minimum training deemed necessary to provide the service? Would such reimbursement practices be successful in encouraging the provision of time-intensive aspects of primary care that would be characterized by both high quality and reasonable cost?

IMPROVING PRIVATE HEALTH INSURANCE

About four-fifths of all Americans, some 181.5 million in 1978, have some private health insurance coverage for hospital expenses and nearly three-quarters, or 164.1 million, are also covered for some physicians' fees (*8*).

The scope and reach of private health insurance give such plans considerable potential for advancing maternal and child health goals that depend upon removal of financial barriers, but this potential remains to be fulfilled. Private insurance plans, at present, do not generally place high priority on the kinds of benefits the Panel deems essential for comprehensive health care of children and pregnant women. Coverage is extensive for inpatient hospital care, but less so for ambulatory care—which comprises the bulk of services needed by children and mothers. Preventive care—again crucial for maternal and child health—is generally excluded. Coverage for any type of care for emotionally disturbed children is very limited.

Regardless of such limitations in private insurance, the fact remains that such coverage is the predominant way Americans finance their health care. Thus, the Panel has considered various ways in which this system



Health care coverage of children and youths under 18 years of age, according to family income: United States, 1976

Notes: Private insurance includes those who have other coverage (e.g., Medicaid) as well. Medicare includes those with no other public or private coverage. Medicaid includes those without private insurance or Medicare and reported either 1) receipt of Medicaid services in the previous year, 2) eligibility for Medicaid as a reason for not having other coverage, or 3) receipt of benefit payments under AFDC or SSI in the past year. Other programs include CHAMPUS, Veteran's Administration, private surgical coverage only and professional courtesy as reasons for holding no other type of public or private coverage. To avoid multiple counting, each individual was assigned to one category only. Persons with both private insurance and Medicare, for example, were placed in the private insurance category. As a result, Medicare and Medicaid estimates do not correspond to counts available from these programs.

might be strengthened. Currently, businesses, labor unions, and individual purchasers of private health insurance have no systematic way to evaluate the coverage offered by various private insurance plans and to rate alternatives in terms of their contribution to health status.

The Panel has concluded that creation of a voluntary and advisory certification process, a "seal of approval" in effect, would go far toward promoting the availability of private health insurance plans that more adequately meet the health care needs of children and pregnant women, by helping to inform purchasers of insurance of the relative strengths of different insurance plans. A similar conclusion was reached by the Congress after it examined so-called "medi-gap" insurance, or policies sold to supplement Medicare coverage.

The Panel recommends that States institute a voluntary seal-of-approval process, whereby state insurance commissioners review private insurance policies approved for marketing in their States and grant certification to those that adequately meet the health needs of children and pregnant women. In determining which policies merit certification, the States should utilize criteria advanced by the proposed Board of Health Services Standards.

If a State fails to perform the certification function, the Federal Government should be authorized to do so. Should the board or its equivalent not yet be functioning, we urge that the Secretary of Health and Human Services request the Institute of Medicine, or some other suitable body, in concert with appropriate professional groups and consumers, to develop such guidelines.

As a contribution to the development of such guidelines, we note below several *characteristics of private health insurance that might form the basis of certification:*

- Coverage of all basic essential services (including prenatal, delivery and postnatal care; comprehensive care for children through age 5; and family planning services), plus such other services identified by the Panel as "needed" as can be provided with reasonable assurance of quality, effectiveness and economy under existing or clearly definable circumstances.
- Coverage not only of the employed or enrolled individual, but also of spouses and all dependent children to age 18.
- Coverage for the entire family, without additional premium payments from the family for 6 months or until comparable coverage is obtained from another source after termination of the enrollee's employment or death, or the divorce or separation from the enrollee in the case of family members.
- Agreement to reimburse all qualified providers in accordance with guidelines provided by the board or other mechanism designated to perform this function.

The standards for certification should not be set so high that few insurers offer, or few purchasers select, the certified plans. The Panel's principal objective is to ensure that a large proportion of children and pregnant women gain coverage from improved private insurance plans within a reasonable period of time—perhaps 2 or 3 years after the establishment of certification standards.

Granting certification to policies that meet or exceed guidelines for providing adequate coverage to mothers and children is only a first step. The Panel urges labor and employer groups to give high priority to the purchase of certified plans; Federal, State and local governments are themselves major employers and can take a leadership role by making such plans available to their own employees and their families. Private health insurers should not only make such policies available but also market them aggressively. In addition, State and Federal Governments and such private groups as the Consumers' Union should publicize the criteria used in the certification process and the results of State review and evaluation so that businesses, labor groups and others responsible for purchasing group health insurance plans will be aware of the determinations.

The Panel considered proposals to require that insurers offer health policies meeting certification criteria, and even proposals to require that employers offer certified policies to all their employees and families. Clearly, such a mandatory approach would be more likely to achieve our objective of improving private health insurance coverage of services needed by mothers and children. We believe, however, that it is preferable to avoid the controversy likely to arise over a mandatory approach and to see if our objectives can indeed be accomplished through a voluntary, advisory certification process.

IMPROVING MEDICAID

The Medicaid program is the Nation's principal system for financing health care for the non-aged poor. Created in 1965 in the same legislation as Medicare, it has the following major statutory characteristics:

- Open-ended Federal matching of State expenditures, at a rate of 50 to 78 percent for benefits and 50 percent for most administrative expenses.
- Broad State discretion in setting income and assets tests for eligibility, and in specifying benefits to be covered.
- State administration under broad Federal guidelines.

Combined Federal-State Medicaid outlays reached an estimated $21.4 billion in fiscal 1979, of which the Federal share was $12.1 billion and the State share $9.3 billion. In that fiscal year, the program served some 10.7 million individuals under age 21 and paid for Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) assessments for some 2.14 million children.

The combination in Medicaid legislation of State autonomy in setting benefits, eligibility, and provider participation policies, and the provision of few incentives for meeting needs adequately, results in enormous variations among States in how the program functions, and tremendous economic hardships and barriers to needed care for millions of families. Twenty-nine States do not allow children of two-parent families to participate in Medicaid, no matter how poor the family. In 19 States, women who are pregnant for the first time do not qualify for prenatal benefits. Income standards for eligibility are so low in many States (a family of four in Tennessee is allowed a maximum income of $2,400 a year to qualify) that the result, in combination with other restrictive requirements, is that only about two-thirds of all poor children are eligible; an estimated 7 million children who meet Federal criteria of poverty cannot receive any Medicaid benefits at all (*9*).

There is considerable evidence that without changes in Federal legislation, the situation will rapidly become worse. Already, between 1970 and 1979, the percent of poor people with Medicaid cards declined in 33 States. Several State legislatures are considering cutting back on eligibility, including denying Medicaid benefits to first-time pregnant women who are now eligible for Medicaid in those States. Projections made for the R. W. Johnson Foundation indicate that if current trends continue, within 3 years, over 750,000 persons now eligible for Medicaid would be made ineligible as a result of more restrictive requirements (*10*).

Medicaid suffers severely from the problems common to any program focused exclusively on the poor—incomplete acceptance by both intended beneficiaries and providers of service, hostility from many of the nonpoor, and constant pressures for service or eligibility cutbacks in times of fiscal constraint. In addition, joint Federal-State responsibility for the program leaves no single level or unit of government fully accountable.

Gaps and turnover in eligibility account for much of the inadequacy of Medicaid in general, and the EPSDT program in particular, in addressing the health care needs of poor children. Only 20 States extend Medicaid eligibility to all poor children regardless of family composition, employment, or marital status, and only 33 cover children in medically indigent families, or those with enough income to meet everyday living costs except for health care (9). Moreover, because family economic circumstances can change significantly from year to year and indeed within a single year, poor people constantly lose or gain Medicaid eligibility. In 1977, some 35 percent of children covered by EPSDT lost eligibility during the year (*11*). Such abrupt shifts in eligibility can seriously interfere with continuity of health care.

Although EPSDT is now the largest health care financing program for poor children, it has not reached its potential. Many States do not reimburse for some of the diagnostic and treatment services indicated by screening results as being needed, nor do they always follow up screening assessments to make sure that detected problems are treated. Various administrative barriers limit or prevent use of health maintenance organizations and other organized settings by many Medicaid-eligible families. Low fees, red tape, and other problems combine to discourage participation in Medicaid by many physicians and dentists. According to DHHS figures, in some States as few as 30 percent of physicians participated in Medicaid in 1973–75. Nationally, just 41 percent of all dentists and about half of all physicians participated (*12*). The rate of participation among pediatricians is considerably higher; recent data indicate 80 percent serve at least some Medicaid patients (*13*). However, the fact that a physician "participates" in Medicaid does not necessarily mean he or she cares for any significant number of publicly subsidized patients. In one State, for example, the data indicate that approximately 15 percent of "participating" physicians filed more than 75 percent of all

Medicaid claims. There is evidence the situation may be getting worse. A Michigan survey found that the percentage of physicians accepting new Medicaid patients had dropped from 83.5 percent to 68.3 percent (*11*).

Some States have been slow to implement the EPSDT program because of the costs involved, even though the preventive effects of the program offer important long-term health benefits and the possibility of lower costs over the long run. With EPSDT, as with Medicaid in general, budget considerations all too often tend to outweigh considerations of beneficiary needs. Although the Federal Government is responsible for enforcement of program standards, the penalty for State failure to meet standards is the withholding of Federal funds—a penalty that punishes the families the Federal Government is seeking to aid.

In volume II of this report, Medicaid, including the EPSDT program, is discussed in greater detail and a number of more specific recommendations are made for its improvement (*14*). In this chapter, the Panel would simply note that even though Medicaid is and will remain an imperfect instrument at best for addressing the health care needs of poor children and pregnant women, many current problems with the program could be ameliorated without changing its basic structure as a Federal-State program focused on the poor. The most important improvements are incorporated in several versions of the Child Health Assurance Program (CHAP) amendments currently pending before Congress; these improvements should be promptly enacted. *Specifically, the Panel recommends immediate action on the following changes in the Medicaid program:*

- *Establishment by Federal legislation of a uniform national income and resources standard, and the extension of eligibility to all children and pregnant women who meet that test, regardless of family status or other conditions.*
- *Coverage of a uniform national package of services, as outlined in the recommendations contained in volume II (14).*
- *Inclusion of all qualified providers, using the reimbursement mechanisms and rate structures that will ensure availability of comprehensive high-quality care for all eligible children and pregnant women.*
- *Federal incentives to the States to provide expanded access to services and appropriate continuity of care.*

NATIONAL HEALTH FINANCING PROGRAMS

We have discussed the ways in which third-party payment policies and practices should be changed to promote the availability, accessibility, and appropriate utilization of needed services for children and pregnant women, and how Medicaid and private insurance should be immediately improved to remove financial barriers to needed care for more families, and to protect people from the economic burdens imposed by high medical bills.

However, even if the improvements we recommend are made, some people will remain uncovered by any form of health insurance, public or private, many health care providers will continue to be unavailable to the poor, and some middle class parents will continue to be forced to choose between health services for their children and the purchase of other necessities.

There is no way to fit existing financing programs together so that many of those most in need of protection will not fall through the cracks, so that a separate and unequal system of health care for the poor will not be perpetuated, and so that all needed health services will be available and affordable to all children and pregnant women, in the absence of a national health financing program.

It is the Panel's conviction that *the health care needs of children and pregnant women will be best served over the long run by a national health financing program that ensures universal entitlement to all. Regardless of how responsibility for funding and administering such a program is allocated between the public and private sectors, all Americans should be included without differentiation on the basis of employment status, economic resources, family structure, or residence.*

Under a universal entitlement program, children and all women share in the general eligibility of the population. There is no need to wrestle with complex and frustrating questions of at what age or situation children or women have a more or less compelling need for services the Panel has identified as essential. There is no point at which benefits are cut off, no arbitrary dividing line between those who are eligible for benefits and those who are not, and no barriers to the use of services as a result of cumbersome, time-consuming and often demeaning eligibility determination procedures, or as a result of fees imposed at the time of service.

The Panel realizes there is a wide diversity of opinion in the Nation about the speed with which a comprehensive national health insurance program can be enacted and implemented. The Panel considered differing views on the best way to begin such a program if a phased approach is adopted, and a majority concluded that *if a universal national health plan cannot be put in place relatively soon, the Panel urges enactment of national health insurance for pregnant women and for children to age 18. If it proves necessary to phase in eligibility even for this population, the Panel recommends starting with a program covering all pregnant women and all children through age 5.**

We consider this last option the barest minimum and irreducible. The consequences of inadequate prenatal care can be so severe, for both infant and mother, that any financing program to benefit child health must begin with adequate care for pregnant women, including comprehensive prenatal care, beginning early in pregnancy. Similarly, coverage of health care costs in infancy and early childhood is essential. Prompt intervention in problems that emerge in the early years after birth, and preventive care during that period, are likely to be more effective than interventions commencing during school years. Although it is undesirable and detrimental to set up arbitrary age categories for eligibility purposes, the Panel would urge top priority to coverage of infants and preschool children if an age cutoff is imposed. The critical importance of both prenatal care and comprehensive care for children through age 5 is discussed fully in chapter 5.

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*One Panel member dissents from this recommendation (see appendix D).

The Panel is well aware that many individuals concerned about improving the health of children and pregnant women would question the wisdom of advocating universal, comprehensive national health insurance in an era of tightly constrained fiscal resources, urging instead that better programs be crafted for those in greatest need. We recognize the legitimacy of the view that in the absence of a program covering all Americans, the gradual extension of coverage should continue to be based on need, and that therefore the next logical step after enactment of the improvements in Medicaid that the Panel has proposed should be coverage of all poor and near-poor adults. The health status and utilization of care of such people is adversely affected by financial barriers; many of them are parents, or women who may become pregnant, and their health is therefore of special significance for a group whose mandate is the improvement of child health.

After serious consideration, however, we have concluded that a program of universal entitlement is decisively preferable to one directed solely at the poor, because when eligibility is tied to poverty status, the results are so detrimental in terms of quality, continuity and appropriate use of care, incentives to economic independence, public support and administrative efficiency, that the price of targeting resources, in this instance, is too high.

No matter how they are structured, means tests inevitably create barriers that prevent or discourage many who need health services from obtaining them. Eligibility tied to poverty status can be lost as soon as the program participant succeeds in gaining a little ground economically—even if the gains are tenuous, temporary or both. Such on-again, off-again eligibility, which is characteristic of the current Medicaid program, not only interferes seriously with the continuity of health care, it also serves to discourage work and self-improvement efforts. Furthermore, even when programs are well designed and administered with sensitivity, many people find it humiliating and demeaning to seek assistance to which they are entitled only because they are poor. Some, indeed, refuse to do so—regardless of how acute their need may be.

The feelings of insecurity, defensiveness, and embarrassment experienced by many beneficiaries of programs targeted solely for the poor are not found among beneficiaries of such universal entitlement programs as Social Security and Medicare, where eligibility is tied to age and other objective and unchanging factors rather than income. It is not only the beneficiaries who feel differently about such universal programs, it is society as a whole. One need only contrast the level of public support, and consequently political support, that exists for Social Security and Medicare with that to be found for Aid to Families with Dependent Children (AFDC) and Medicaid.

Because of such public attitudes, and because of the inescapable problems inherent in any means test for eligibility, it will always be difficult, if not impossible, to enact a health care program for the poor and only the poor that fully meets the health care needs of the target population, and to keep it funded at the necessary levels. As former Social

Security Commissioner Robert Ball has written, "The best way to develop a program for low-income people that is well administered and respectful of human dignity is to include low-income people in exactly the same program that serves the rest of the population—not simply an income-tested program administered by an agency that serves the general population. Programs designed solely for the poor do not get the same sustained interest and support as programs that serve us all. Whenever the budget is tight, it is the programs for the poor that are likely to suffer" (*15*).

There are three additional problems with health care programs targeted for the poor that deserve mention here. The first is the sizable administrative burden involved in creating and applying eligibility tests to millions of people each year, and the considerable costs that go with it. The second is the fact that programs limited to the poor lose most of the opportunities that are offered by universal coverage—even for mothers and children alone—to achieve a more rational allocation of resources and effective controls over costs. The third, and most troubling, drawback is the tendency of such programs to create and perpetuate two separate and unequal classes of health care. Thus, although one of the goals of Medicaid was "... to provide the poor with the same access as the rich to mainstream medical care," data from national household surveys indicate that the proportion of low-income persons with a private physician as a regular source of health care actually *declined* following the enactment of Medicaid, from 63 percent in 1963 to 56 percent in 1970. The use by the poor of public sector sources of care increased during that time (*16*).

Although taking no position on the issue of how a national health insurance program should be financed, the Panel is aware that if a program involving a mix of public and private financing is adopted, some way of determining the source of contributions for beneficiaries would have to be devised. We believe this could be done in a manner that avoids the major problems of means tests discussed above.

For all these reasons, we therefore encourage creation of an advocacy coalition to press for enactment of a universal maternal and child health insurance program. Those whose primary concern is the health care of children and those whose principal focus is on national health insurance for all should find ample grounds for cooperation in support of such a program. The former should welcome an approach to child health that eliminates gaps in coverage and discontinuities in eligibility status; the latter should take heart from a major extension of the universal social insurance approach to health care beyond its present beachhead, Medicare.

Whether a national health insurance plan applies to all Americans or only to children and pregnant women, *all services defined by the Panel as "needed" should over the long run be covered in full, without cost sharing by the patient or family. All basic essential services (prenatal, delivery and postnatal care; comprehensive care for children through age 5 and family planning services) must be so covered from the inception of any plan. The program should also cover, from its inception, such other "needed" services as can be provided with reasonable assurance of quality,* *effectivenesss, and economy under existing or clearly definable circumstances.**

As we have said before, the three clusters of services we have defined as basic and essential are so crucial to the health of children and pregnant women that all barriers, financial and otherwise, must be removed to ensure they are widely available and accessible. Those services that are difficult to define precisely, or that raise other special problems, would be referred to the proposed Board on Health Services Standards for guidance regarding the circumstances in which they should be covered.

The Panel recognizes there will be controversy about our goal that over time all needed services be covered without cost sharing by the patient or family. It is unquestionably true that cost-sharing devices such as deductibles or copayments hold down the costs incurred by third-party payers, whether public or private. They do so in part by deterring utilization, and in part by shifting those costs onto the patient and his or her family. Unfortunately, there is no way to ensure that only "unnecessary" utilization of health services will be deterred by a requirement that the patient foot part of the bill. Many a stomach ache will pass of its own accord without the expensive assessment of a physician, but a small percentage will turn out to be acute appendicitis or some other condition requiring immediate medical intervention. The mother who decides against a trip to the doctor for a child with a stomach ache because she will have to pay some part of the bill is ill-served by a health plan that requires patient cost sharing. The deterrent effect is even stronger in the case of preventive care, where no immediate need for services may be perceived by the patient or parent. Yet it is precisely these services of disease prevention and health promotion that are essential to the health of mothers and children, as we have repeatedly stressed.

Although studies indicate the poor are most likely to be deterred from seeking care by cost-sharing requirements, they are not alone. Indeed, there are ways—albeit cumbersome and expensive to administer—to waive such requirements for individuals or families meeting various means tests. People of all income levels are usually reluctant to spend money "unnecessarily," and may not recognize the full value of some types of care or the medical need for others. Adolescents, for example, have only limited access to money they can spend as they wish and are especially likely to be discouraged from seeking health care—including important services like family planning, venereal disease examination, and crisis counseling—if they must pay some or all of the cost. Deductibles and copayment requirements generally complicate and add to the cost of insurance administration, eating up funds that could otherwise be applied directly to payments for services. Such requirements make it difficult for patients and providers to know when benefits are due or how much they will be. If they are to be adjusted or waived for the poor, means tests are necessary—and we have already described our objections to such tests.

There are, of course, individuals who make excessive visits for medical care. However, studies in Canada and of prepaid plans in this country indicate there is no increase in numbers of "overutilizers" when medical care becomes "free" (*17, 18*). In fact, most costly forms of overutilization are the product not of consumer behavior but of provider decisions—excessive prescription-writing, unnecessary surgery, inappropriate hospitalization and excessive use of laboratory, radiologic, and other diagnostic procedures. In the words of Drs. Jonathan B. Kotch and C. Arden Miller of the University of North Carolina, "Cost-sharing places an economic burden on consumers for a problem which is generated by providers and which might better be dealt with by means of standard setting and quality control" (*19*).

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*One Panel member dissents from this recommendation (see appendix D).

A number of the national health plans put forward in recent years have been classified as "catastrophic" or "major medical" health insurance. These would cover health care expenses only after the patient or family has satisfied a large deductible. The deductible may be expressed in a variety of ways—total dollars, percentage of income, number of units of services used or combinations of all of them. Most such proposals contain means test provisions and special coverage for the poor.

Although any national health financing program must include coverage of catastrophic, or major medical, expenses, the Panel opposes a program limited to such coverage because it would do nothing to enhance the availability and use of the health services most needed by children and pregnant women. Indeed, as economist Alain Enthoven has written on the subject of such a "major risk" approach:

> The effect would be to pull medical resources out of ordinary "primary" care and into the care of "catastrophic" cases, to an extent even greater than occurs today. This would mean less emphasis on activities that can help prevent disease and add significantly to the quality of life, and more emphasis on care that offers small or negligible net benefits at very great cost. It would mean a reallocation of health care resources toward categories of care that are probably accounting for too high a share of health care expenditures now. It wouldn't solve the problem of the irrational incentives. It would merely focus them on the most costly cases and forms of care (*20*).

For all of these reasons, we reiterate our support for a national health financing program that provides universal entitlement and coverage without cost-sharing requirements.

IMPROVING GRANT PROGRAMS

Grant programs are today, and will continue to be, an important mechanism in a national strategy to assure that needed health services will be available to all mothers and children.

Although the Panel looks forward to the day when virtually all personal health services for children and pregnant women will be financed through a national health insurance program, grant programs will continue to play a major role until that time, and with some modifications will be an essential accompaniment to national health insurance after its enactment.

Now and in the future, to help assure the availability and accessibility of individual health services, the Panel supports the use of expanded grant programs to:

- Subsidize the development of resources in geographic areas where the personnel, facilities or delivery mechanisms to provide needed services are unavailable, and to finance demonstrations of new and better ways to deliver needed services.
- Pay for needed services that are clearly more appropriately financed through grant programs than through third-party payments, and for those where more information is still needed regarding the most effective methods of payment.
- Pay for comprehensive services for persons such as handicapped children who have distinctive service needs best met through special systems or programs.
- Pay for needed services for those persons lacking other sources of payment, such as migrant workers, illegal immigrants and poor individuals not eligible for Medicaid.

Many Americans live in areas where needed services are not now available and are not likely to become so under prevailing third-party financing arrangements, or even with improved third-party payment programs. Inner city neighborhoods and isolated rural communities are the prime examples. Although many innovative health care delivery and manpower programs were developed in the 1960's and 1970's to make health services available in such communities, the supply as yet does not match the need. Considerable additional grant funding will be needed to reach underserved populations through new or enlarged community health centers, children and youth projects, hospital-based primary care units, comprehensive public health department programs, and similar projects. The Panel would urge that additional funding be provided to organized health care delivery settings that meet the primary care unit attributes described in chapter 6. Grant funds should also finance demonstrations of new and better ways of organizing and delivering health services to children and pregnant women. First priority in the award of both resource development and demonstration grants should go to areas with the greatest need.

The services rendered in delivery settings established with grant funds should be financed increasingly over time with third-party payments. The efforts undertaken jointly in recent years by the Health Care Financing Administration and the Public Health Service to enable facilities that are financed in part by grants to apply for and obtain reimbursement from Medicaid and other third-party payers should continue and be intensified and expanded.

In the absence of a national health financing program covering all children and pregnant women, grant funding is also needed for financing certain of the services the Panel has identified as "needed," including and beginning with the minimum basic services (prenatal, delivery, and postnatal care; comprehensive care through age 5, family planning services) for those individuals with no other source of payment, public or private. Grants for this purpose can go to various service providers, supplementing existing programs and sources of funds.

The Panel also recommends the use of grant funding for certain services, such as preventive dental care, which can be rendered most economically and with the greatest chance of reaching everyone in the target population when payment flows directly from a granting agency to the service provider in a lump sum.

Other services have been identified by the Panel as essential, but most likely to be effectively rendered under circumscribed conditions. Counseling and support to help a pregnant woman stop drinking or smoking would be an example. While the proposed Board of Health Services Standards, or a similar mechanism, is seeking to define precisely how such services should be delivered and by whom, they are best funded by lump-sum grants to providers who make systematic provision for onsite review of quality and effectiveness.

Finally, there are services that assist individuals or groups with special access problems to make timely and appropriate use of health care services. These access-related services, such as transportation, outreach workers, translators, etc., are often most effectively funded through grants. The need for grant programs to finance comprehensive services for persons, such as handicapped children, who have distinctive services needs that are best met through special systems or programs, and for persons with special access problems, such as migrant workers and illegal immigrants, is discussed in chapter 8.

POSSIBLE NEW REVENUE SOURCES

Because it may be difficult to count on significantly increased appropriations for health and social service programs at either the Federal or State level in the near future, the Panel has examined a number of alternative means of raising funds for health services needed by children and pregnant women. One we consider interesting enough to merit further study is based on a pattern that is already in use in many States, in which insurance regulations result in what is in effect a subsidy of high-risk groups. We urge further consideration of proposals to require private health insurance companies, and possibly Medicaid and certain other Federal programs, to contribute a fixed amount of their income to be utilized by the States for the following purposes:

- To fund public health, preventive or other services not readily insured.
- To fund resource development activities, including planning, start-up and initial operating grants for primary care services in underserved areas, and services not otherwise available.
- To subsidize third-party health insurance costs for those children and pregnant women who could not otherwise afford such insurance.

This proposal represents a way to raise funds for public purposes through a method other than direct taxation, and a way to have purchasers of insurance compensate for some of the weaknesses of insurance. Thus, purchasers of dental insurance would help subsidize fluoridation activities—which cannot be paid for through insurance, yet are vital to good dental health—and reduce payments for dental benefits. Such an arrangement would also have the effect of limiting some of the problems caused by experience rating.

There are, of course, significant problems with this proposal, including the relationships such an approach implies between private and public sectors. In addition, raising funds in this way may be considerably less progressive in its taxing effects than a direct tax would be. Nonetheless, the Panel suggests this idea be studied further, along with any other innovative revenue-raising proposals that may be advanced with a similar potential for providing urgently needed new funds for improving maternal and child health.

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SECTION IV

GOVERNMENTAL RELATIONSHIPS

CHAPTER 10

STRUCTURING THE SYSTEM

Preceding sections of this report outline a number of steps that should be taken to advance the health of children and pregnant women. These recommendations span issues of health protection and promotion, define services that should be available to these populations, and discuss problems in the organization of health services. We call, for example, for the assurance of universal access to a set of basic, essential services; for the extension and improvement of regionalized programs of perinatal care, tertiary care centers for specific chronic illnesses and handicapping conditions, and emergency care networks; for the development of community-based programs identifying and meeting the health care needs of children with physical, mental and emotional impairments and chronic illnesses; and for the development of a broad range of efforts in preventive care and health promotion.

It is our conviction that many of these objectives can be reached without the creation of major new public programs. What is needed, instead, is a concerted effort to coordinate existing programs, clarify responsibilities of those making policy and administering programs, and achieve a broader consensus on the importance of maternal and child health generally and of certain needed steps specifically. Achieving better coordination and program management will not be easy in a mixed private and public health care system such as ours, where policy control is diffused across many different providers, professional groups and levels of government. The pluralism of provider arrangements we specifically advocate in chapter 6 complicates greatly the task of bringing more coherence to the delivery of health care services; and intersecting responsibilities of local, State, and Federal Government make policy formation and program administration complex. However, in spite of such constraints, the Panel believes that the joint effectiveness of existing programs and activities that bear on maternal and child health can be greatly increased.

We have been deeply impressed throughout our hearings, site visits, and analyses with the widespread concern regarding problems of program fragmentation and splintering; of insufficient clarity in the division of responsibility among local, State, and Federal authorities; and of inadequate local service coordination. These problems are creating both confusion and gaps in the delivery of services to mothers and children, particularly the most vulnerable among them. In the face of such problems, this chapter takes up the complex issue of how private providers, professional organizations, and public officials at all levels of government should work together in making needed changes.

Because the evolution of Federal programs for mothers and children has been a very significant—though often inadvertent—factor in creating complexities of program management and policy formation at the State level, it is useful to review briefly the major changes in Federal maternal and child health policy which have taken place over the past 75 years, and to see how these have both assisted and caused difficulties for the States. The following section summarizes pertinent developments.

AN HISTORICAL PERSPECTIVE

Federal programs for mothers and children usually have developed by small incremental steps. However, there have been at least four times when the Federal maternal and child health programs of the day were determined to be inadequate, precipitating a major restructuring of the system. These periods of major ferment led to the creation of the Children's Bureau in 1912, the enactment of the Sheppard Towner Act in 1921, the passage of Title V of the Social Security Act in 1935, and the passage of various targeted health service programs in the 1960's.

The Children's Bureau was created in 1912 because a small group of wise and foresighted people were concerned that the Nation's mothers and children were not receiving needed health services. After it was established, one of its first tasks was to identify the major health needs of special groups of mothers and children: children in families receiving public aid, children deprived of parental care, mothers in industry, children in day care, children in juvenile courts, children in institutional care, and illegitimate children. Not only did the Children's Bureau study the health problems of these groups, it was also instrumental in promoting legislation to correct the identified problems. It prompted enactment of State laws to improve the care of the institutionalized dependent child, State laws to create juvenile justice legislation, and State laws concerning illegitimacy. It is interesting to note that with few exceptions, the Children's Bureau did not create Federal programs but encouraged the States to pass legislation creating their own programs, indicating the dominance of State government over Federal Government in human service programs at that time.

Before the creation of the Children's Bureau, the Federal Government accepted no responsibility for the health of mothers and children. The creation of the Children's Bureau changed that, but the responsibilities given to the Bureau were actually quite modest. The Bureau's primary duty was "to investigate and report" about the health of mothers and children. From that simple mandate, the Nation's complex public policy concerning Federal and State responsibilities for mothers and children has evolved.

Although the creation of the Children's Bureau was an important step forward, it was really no more than an office in the Federal Government that served an advocacy role for mothers and children. Its limited staff was involved primarily in collecting information about the health status of mothers and children, and relied heavily on an advisory committee for its policy determination and lobbying activities.

The next turning point in maternal and child health legislation was the passage of the Sheppard Towner Act. The Children's Bureau helped sponsor this legislation, which reflected concern about the high infant mortality rates that existed among poor infants in cities. The Sheppard Towner Act was an important milestone in the evolutionary development of public policy concerning Federal and State responsibility for the provision of health services for mothers and children, because it established that the Federal Government could encourage States, through grant-in-aid programs, to provide direct health services.

The next cycle in the development of Federal legislation for mothers and children started with the passage of the Social Security Act and Title V of that Act. The Children's Bureau, which developed Title V, was concerned that many mothers lacked access to prenatal services and that many children had no access to well-baby and well-child care. What resulted was the creation of the State Maternal and Child Health programs. Concern for the unmet needs of children with chronic diseases and disorders also led to creation of the State Crippled Children's Services programs. Again, a gap between the health services available and the health services perceived to be needed was a major factor in overhauling the Federal effort.

The responsibility of both Federal and State Government in the provision of health services for mothers and children was vastly expanded with the enactment of Title V. The new legislation established a strong Federal-State system concerned with the health of mothers and children, a system in which the Federal Government was to have a major responsibility. In part, this was to be achieved through the grant-in-aid policy that had been established by the Sheppard Towner Act. In part, it was to be achieved through extensive Federal regulations specifying what services the State programs were to provide, and how State programs were to provide them. State programs were required to comply with these regulations to be eligible for the grant-in-aid. The regulations put teeth in the grant-in-aid process and established the Title V agency as a strong Federal presence responsible for mothers and children, which still continues today.

The policies established by the original Title V legislation remained essentially unchanged until the amendments of 1963 and following, creating the Maternity and Infant Care (MIC) and Children and Youth (C&Y) projects. This legislation allowed the Federal agency to circumvent State government and negotiate directly with other responsible bodies to create community health units, a departure from previous policy that the Federal Government would work only through State agencies. The change was made because in the judgment of the Congress, the activities of many States were not adequate to meet pressing maternal and child health needs and opportunities. The precedent was thus established that the Federal Government as well as State governments should assume responsibility for working with local communities and public and private agencies to meet maternal and child health needs. This policy of course was not limited to Title V health programs; it was common to many of the Great Society programs.

During the 1960's, a number of categorical programs were also created to provide services for specific diseases or health problems that had been identified by the revolution in medical knowledge. The American health care system had become more oriented toward the treatment of acute diseases, and various organizations and groups who were interested in particular diseases and disorders lobbied to create free-standing Federal programs to provide relevant services. These included programs for renal dialysis, hemophilia, various forms of chronic pulmonary disease, and genetic diseases. Again, recognized health needs caused major changes in public health programs.

Creation of the various categorical health programs for mothers, children, and poor families during the 1960's resulted in a number of vertically organized programs. Some were developed to function within the traditional Title V Federal-State organization, but more were designed to function as semi-independent units with varying degrees of organizational attachment to the State programs, and a number were designed to function as free-standing programs unrelated to the Title V Federal and State organization.

Since the 1960's, the problem of diffusion of policy and program control has been heightened by a number of factors. Major additional Federal policy initiatives—including the child nutrition programs, the Education for All Handicapped Children Act, the Title XX legislation, the expansion of Head Start, and others—have taken place outside the health sector, even though these programs are clearly health-related. State health departments and others responsible for the coherence of State maternal and child health efforts have found it difficult to coordinate these new programs with existing ones. Likewise, as demands on State governments have grown over the past 20 years, many States have reorganized their human services agencies into umbrella organizations, subordinating their departments of health and placing maternal and child health and child care programs lower than ever before in the State government structure (*1*).

Finally, the very real fiscal crisis of many States and localities in the 1970's has made it difficult for States simply to maintain the scope and quality of many existing services. As inflation and reduced program budgets have taken their toll, bureaucratic problems have often become worse rather than new efficiencies being realized. Each State agency or program unit has found itself competing with others for limited public service dollars, with increasing pressure from its own constituencies and often with another set of pressures resulting from accountability requirements of various Federal programs.

BASIC ASSUMPTIONS

The Panel believes the current disarray of programs and policies is sufficient to merit another major step in the Nation's policy toward children and mothers, this time to integrate program policy as well as oversight and management. The balance of this chapter offers some suggestions in that direction. In so doing, the Panel wishes to make explicit some of the assumptions we have come to share in the course of our deliberations, all of them relevant to our views about an adequate national policy; most have already been touched on elsewhere in the report. We do so in recognition of the fact that in any discussion of health care policy, individuals harbor many different frames of reference and value assumptions. This is especially true in a country like the United States, where patterns of care diverge so widely for different population and income groups, and where the appropriate scope of private and public responsibility is constantly being renegotiated.

(1) At all levels of policy determination and governance, we believe that health policy toward children and pregnant women should be construed broadly to encompass a wide range of health and health-related services, both private and public, including primary health care, nutritional interventions, family planning, mental health care, specialized services for chronically ill and handicapped children and others at special risk, local and regionalized hospital care, school-based health services and relevant support services. Because the private sector plays such a major role in delivering services, establishing standards of care, and training professionals, it is not enough to equate maternal and child health policy with public policy alone or with publicly provided services, or even with publicly financed services. In addition, we have argued throughout the report that health care spans a good deal more than traditional medical services, and that health-related educational and support services must be part of a comprehensive national health promotion policy for children and mothers.

One good illustration of how major policy initiatives are likely to require close partnership between the private and public sectors, and to include a wide range of services, is found in recent efforts to improve pregnancy outcomes. As a distinguished physician testified to the Panel:

> [Federal authorities were] able to delineate Federal project grant funds for Neonatal Intensive Care units (NICU). Later it was mandated the NICU's be supported by maternal and child health funds in every State. However, it was the private sector which spent considerable time, effort and money to develop the milestone document "Toward Improving the Outcome of Pregnancy"; and it was the enthusiastic, unflagging and vigorous efforts by the young neonatalogists in this country who led their communities, hospitals, health departments, State legislatures, etc. to put into place a regionalized system, including transport, for the care of newborns requiring secondary and tertiary care. And they, and to a gratifyingly increasing extent, their colleagues in Obstetrics are still exerting leadership to expand and improve regionalized perinatal care. I am convinced that if the private sector had

not done so, this country would not be close to the level of care now being afforded the high-risk newborn (*2*).

Collaboration between private and public providers also has been characteristic of many other major policy developments, including implementation of the EPSDT program, the development of school-based services for adolescents, and community education in accident prevention.

(2) Although many of those most in need are likely to be poor and poorly educated, a national policy must address the needs of *all* children and pregnant women. In assessing needs or in planning, for example, it is not sufficient to address only the problems of low-income families or groups eligible for means-tested programs. To do so not only overlooks the very real health needs of certain other population groups with special needs (e.g., adolescents), it also tends to obscure the fact that many children and women move in and out of poverty status each year (*3*).

(3) The development of lists of needed services, as found in chapter 5, and the description of desired attributes of every primary care unit, as found in chapter 6, make it easier to delineate desirable goals and organizational structures of primary care. But the Panel also believes that pluralism of provider arrangements is desirable, permitting greater freedom for consumers and health care professionals alike. This diversity inevitably makes policy formation more complex.

(4) We believe that only at the levels of government closest to children and families—the Nation's towns, cities, and counties—can health care needs be assessed in detail, and services organized to meet these needs. Although many decisions regarding program priorities, policies and budgets necessarily are made at more distant levels of government, these levels should see it as their role to facilitate and enhance the efforts of local providers and local government. Because the strength of service systems in the United States lies in their pluralism and their appropriateness to diverse local realities, it is essential that flexibility be preserved in the various instruments of State and Federal assistance. Conversely, over the coming decade more should be expected of local elected officials and providers in assessing the needs of resident children and families and taking the initiative to further develop and coordinate existing services so that all persons are adequately served.

Community participation in the design of local service structures also leads to grass-roots support of health services. Communities with no sense of involvement in local health programs are not likely to be committed to maintaining and strengthening them, whereas those with strong commitment often can overcome considerable financial, organizational, and political barriers to ensure that basic services are available to all.

(5) Stronger orientation to health promotion and preventive care for children and pregnant women implies a fundamental shift from passive to active modes of service. Health professionals and

institutions must be attuned to reaching out to engage individuals before health problems become serious. Providers often operate on the principle that it is enough to treat conscientiously those who come through the door. Responsible local authorities must compensate for this posture and overcome it where possible by anticipating the needs of defined population groups, and working to mobilize private and public health care providers as a group to meet preventive care needs. Outreach activities are essential to this more active approach. Emphasis on prevention also calls for closer collaboration among environmental protection, public health and personal health care professionals, with division of responsiblity among them clearly defined. The economies that result from unified efforts in screening, accident prevention, and other essential activities are certainly in the interest of local authorities to encourage, but may require reordering of political, bureaucratic and professional "turf" over a period of years.

Similarly, attention to psychosocial and behavioral problems of children and their families requires coordinating the efforts of private and public health care providers, school and social service personnel, and mental health professionals.

(6) We have argued that family involvement is essential in children's health care, and that such care cannot be delivered effectively without acknowledging the centrality of parents and other significant persons in the child's community. In many forms of health care and especially for chronically ill or handicapped children, the nature of the child's social environment becomes a major determinant of success or failure. One major challenge facing local service systems is to design case management so as to simplify service use for the child and parent, and to build on strengths and sources of support for the child in the community.

In addition, a number of the Panel's recommendations aimed at assuring that all infants, children, adolescents, and pregnant women get the health services they need, must be implemented with particularly great care to enhance and not undermine family integrity, privacy, and confidentiality. Our recommendations to expand home visiting to families with pregnant women and newborns, and to monitor more closely the availability and utilization of certain health services, raise especially important issues in this area. We believe the significant health objectives of both of these recommendations can be realized without compromising family integrity, privacy, and confidentiality, but special attention must be paid to ensure that progrm participation is voluntary and that health care personnel do not interfere inappropriately with a family's customs, values, and lifestyle.

(7) The Panel is impressed with the evidence gathered from the literature, from testimony of interested groups, and from our site visits and consultations that public programs that are successful in reaching a high proportion of their target population with

primary care tend to have a significant component of parent or consumer involvement. Such involvement can take many forms, including true partnerships in which program control is shared between providers and users of services, advisory bodies, and arrangements where parent or consumer influence is exercised primarily by employment of community residents in paraprofessional roles. Especially where there is a substantial social or cultural distance between the target population and those who are providing services, genuine and systematic involvement of consumers will considerably heighten the chances of successful operation of the program.

(8) Last, we caution that movement toward full attainment of national objectives will require forceful private and public leadership, as well as extensive collaboration among health care providers, policymakers, parents, and other citizens. Such leadership and collaboration cannot be willed into existence by the Panel, nor can changes in current patterns of service delivery and program administration simply be "engineered." No number of specific recommendations for new standards of care, program reforms, altered regulations, or new administrative structures can substitute for the resolve of individuals working together to bring about desired changes. We believe that broad support of basic maternal and child health objectives themselves, and willingness to work aggressively toward their attainment are among the most important predictors of success. We also believe that progress toward these objectives is measurable, with a variety of process and outcome measures available to those who would prepare a national report card 10 years hence.

MAJOR OBJECTIVES OF STRUCTURING THE SYSTEM

The chief goal of the restructuring ideas presented in this chapter is to integrate and conform policies in existing programs to better serve the needs of children. Each program—whether Federal, State, or local—ought to contribute to the objectives set out in this report through program activities that work well collectively. The Panel recognizes that targeted funds and special programs are in many cases essential to meet the needs of particular populations. Its recommendations thus are not aimed at reducing or consolidating programs as a goal, but rather at directing the efforts of existing programs toward mutually reinforcing ends. The Panel believes the key challenge with regard to the range of existing programs is to integrate their policies, reporting, and administrative activities. The remainder of this chapter is devoted to recommendations toward this end.

GOVERNMENTAL ROLES

In chapter 1, we briefly reviewed various factors that contribute to the complexity and fragmentation of current policies, programs and local delivery arrangements. Variations are great among States and localities in the way these factors play themselves out and interact, making it difficult to comprehend in detail their impact on the quality and efficiency of care.

The Panel wishes to be candid in saying that during our 18-month investigation, we could not hope to fully understand all of the relevant administrative, bureaucratic, and intergovernmental implications of these issues or to comprehend the intricacies of service systems in all 50 States. In addition, it is obvious that many of the most serious questions about how best to clarify and improve national policy toward the health of mothers and children cascade into larger questions of how best to organize and administer human services as a whole, how such efforts should link with policies for other target groups, and so forth. It is beyond the scope of this report—or any single report—to analyze such questions comprehensively.

We nonetheless believe that it is possible to shed some light on many of the basic problems currently facing State and local providers, professional groups, and policymakers categorized under three broad rubrics.

- State management structures
- The relationship between State and Federal Governments
- Local service coordination

The sections that follow analyze each of these. A fourth category—strengthening administrative structures at the Federal level—is discussed in the next chapter.

State Management Structures

The Panel is aware that in many States a mandate to carry out our proposals is unrealistic unless the scope of State policy is reconceived and an appropriate structural unit, budget review process, or both is initiated. Our willingness to advocate a major continuing role for the States is critically dependent on the willingness of the States to accept the new role in its full substance. The Panel does not wish to propose a single agency configuration, believing that effective leadership for maternal and child health might be designed quite differently in different States. But we do make the following recommendations, all of which would help to create a more effective focus for maternal and child health at the State level.

First, *every State, through the office of the governor, should review its options for consolidation of program effort related to maternal and child health and attempt to place authority over all relevant funding streams in an appropriate division based in the State health unit.* We believe this can and should be done in States with umbrella agency structures. Options include joint budgeting, colocation, and shared administrative control as well as full integration. Present experience suggests that States where maternal and child health is equated with Title V only do not have the critical mass of dollars or program control needed to achieve the objectives we have outlined. Conversely, some States such as Michigan and Alabama have set an important precedent by unifying policy control of Title V, EPSDT, Family Planning, and the WIC program under a single health department unit. States that do not actually consolidate programs or at least policy control should be required to explain, as part of the Title V reporting system, how the Title V agency is coordinating with EPSDT, WIC, and Title X Family Planning. All States should further be required to include in their Title V reports impact statements regarding coordination with mental health services and services for the handicapped, including those offered under P.L. 94–142 in the schools. Reporting requirements that conform with each other, created by appropriate Federal authorities, should be an option for States that seek to integrate program management or policy. For the remainder of this chapter, the proposed new State administrative mechanism will be referred to as the maternal and child health authority.

Second, *in those States where Title V Crippled Children's funds are administered in a separate agency, a department of welfare or a university, this unit should be closely linked for purposes of planning, data collection, and quality assurance with the maternal and child health authority.* A strong unification of effort should be promoted around all aspects of care for handicapped children. The Panel hopes that the term "Crippled Children" will be replaced in the 1980's by a term more in keeping with today's wide range of programs, such as specialized health services for children. The unit or process responsible for making State programs for handicapped children work together should not only oversee expenditure of Title V funds but also provide focus and leadership on health-related policies of all State programs for physically and mentally handicapped children.

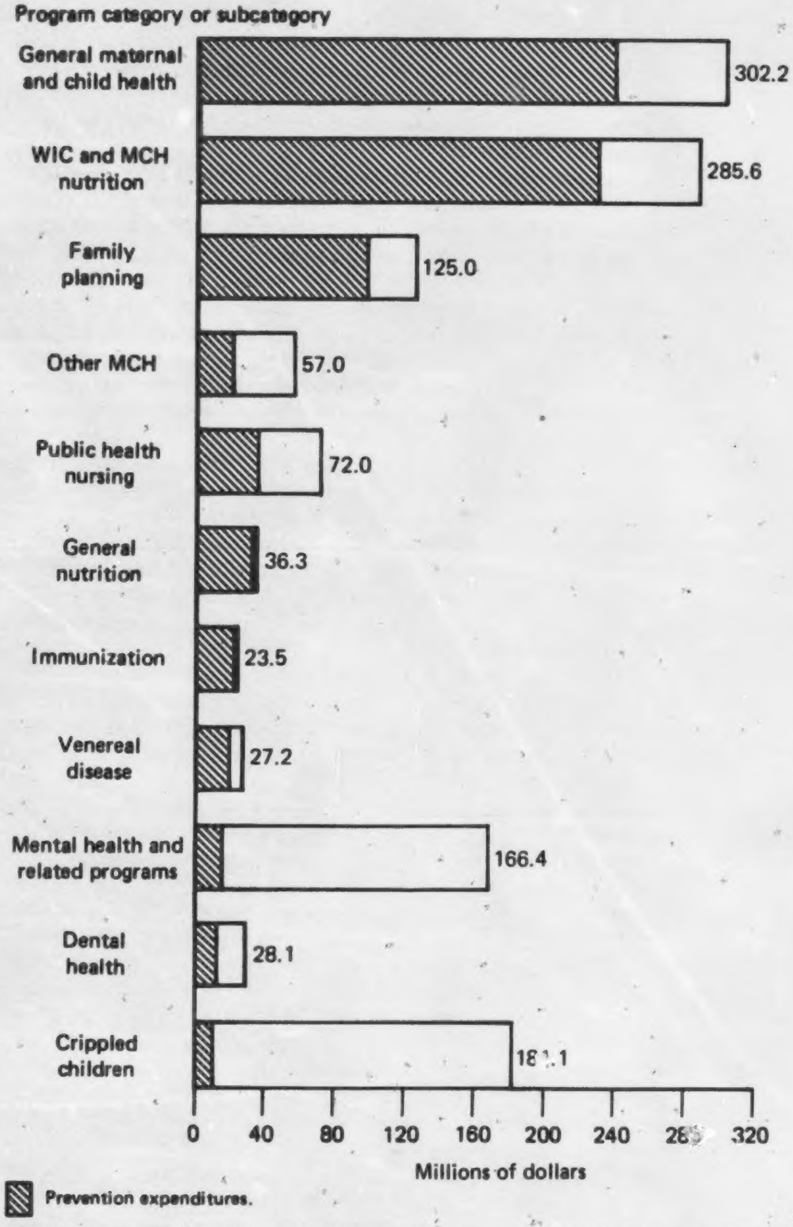
And third, *the Federal Department of Health and Human Services (DHHS) should familiarize those States demonstrating only minimal consolidation or coordination of programs with policies and practices that have simplified bureaucratic structures in other States.* These efforts should involve more than just health personnel—they should also be targeted to State legislators, health planning agencies, consumer advocates, budget directors, and the governors themselves.

State-Federal Relations

It is a major positive step to establish a clear unit or mechanism of responsibility at the State level for various programs related to health care for children and pregnant women. Equally important is a clear understanding between the States and the Federal Government about the role of each in the process of policy formation and program implementation.

The Panel recognizes the well-established tendency for one level of governance to insist that problems of organization must be solved at another. Hence, State authorities urge that Federal programs be reorganized before the States can act, while Federal authorities stress the flexibility of current legislation and regulations and blame State and local program managers for not being more resourceful in joint efforts and in marshalling various resource streams. This pattern is not conducive to effective program implementation.

A first step in clarifying State-Federal relations is simply to define what it is that each of these levels of governance should be expected to do in the



Total personal health expenditures and personal health prevention expenditures of State health agencies, according to program category and selected program subcategories: United States, FY 78 process of policy formation and implementation of public programs. The Panel believes the following division of responsibility is reasonable and preserves a strong collaborative relationship between State and Federal Governments.

Federal responsibilities (including both Congress and the Executive Branches as appropriate) should be to:

(1) Identify the personal health services that should be available to all mothers and children; determine the special health services that should be available to mothers and children who have special needs; and determine the health promotion and prevention services that should be available on a population basis.

(2) Establish and fund programs, as needed, to support health services for mothers and children; conduct traditional and innovative health promotion and prevention programs; and, conduct relevant research and demonstrations, training, technical assistance, resource development, and advocacy on a national basis.

(3) Establish a comprehensive maternal and child health planning system that functions within the national health planning system (*4*) and will be used by all relevant Federal programs. The planning system should (a) identify the health services that are needed by mothers and children, (b) describe the health services that are to be provided mothers and children by public programs, and (c) help to improve existing services and develop new resources as needed.

(4) Establish a common reporting system for all relevant Federal programs. The reporting system should (a) require evidence that needed health services are provided, (b) require evidence that standards to ensure quality of services have been established and met, and (c) require evidence of improvement as a result of the services (improved health status indicators, more services provided at an earlier age or earlier stage of pregnancy, improved levels of compliance, greater consolidation of services, reduced costs).

(5) Provide technical assistance to the State in developing State health promotion and prevention programs.

(6) Determine if a State has met the performance criteria for providing needed services. If such is not the case, Federal authorities should work directly with others in the State to assure that needed services are provided.

Leadership in all of these matters should be assigned to a new Maternal and Child Health Administration, as described in chapter 11.

State responsibilities should be to:

(1) Work cooperatively with other State-level planning bodies (health department, State Health Planning and Development Agency, State Health Coordinating Council, and American Academy of Pediatrics and other professional groups) to identify the health services needed by mothers and children of the State. The services must include, but need not be limited to, the federally determined services. Based on this information, a plan

should be developed congruent with the overall State health plan.

(2) Authorize programs and appropriate funds to achieve major health objectives for children and pregnant women, both as a match for Federal support and independently.

(3) Support and encourage communities and regions to develop maternal and child health service units to provide coordinated patient services.

(4) Develop and support on a regional basis those health service programs that for logistical or cost reasons cannot be developed locally.

(5) Provide certain health promotion and prevention activities on a statewide basis, and encourage promotion and prevention activities in primary care units at the community level.

(6) Interpret Federal standards of care, and also monitoring health service programs to be sure these standards are met.

(7) Use federally determined health planning and reporting methods, with appropriate adaptations to accurately report the health needs and health services of the State.

(8) Carry out the additional responsibilities of support for research and demonstrations, resource development, advocacy, and program coordination so as to permit the attainment of major policy objectives.

(9) Create a conduit for consumer ideas for improvement of services and a grievance system for those who may be denied services to which they are entitled.

We offer such guidance mindful of the fact that the major dilemma of State-Federal relations at present is how to achieve appropriate State autonomy in the organization and control of relevant programs while at the same time ensuring equity of service access and quality across the various States and accountability for Federal program funds. With the exception of certain grant programs such as the Community Health Centers and Head Start, most Federal maternal and child health funding continues to allow substantial State initiative and discretionary authority to determine program scope and intent. As we have indicated in previous sections, we support this pattern and believe that the proper national policy for the coming decade is one that makes full use of the capacity of the States in maternal and child health.

If future policies increase the discretionary authority of the States over expenditure of Federal dollars, however, two issues arise that cannot be dismissed lightly. First, it is clear that without sustained or significant increase in Federal control over program performance and targeting of resources, major inadequacies and inequities are likely to persist in some States. It is very difficult to establish criteria or procedures which would allow some States but not others autonomy in the direction of Federal programs. Hence, the Panel is reluctant to suggest that State control over Federal categorical programs be increased, except in selected realms such as planning. In particular, we specifically reaffirm the need for the Federal Government to retain the ability to make direct grants to communities to meet important health needs that a State cannot or will not address. This view is consistent with the recent recommendation of the General Accounting Office that State maternal and child health agencies not control Federal categorical programs but be given the opportunity (1) to review and comment on applications or plans required prior to funding award and (2) to participate, to the extent practical, in monitoring and evaluation activities (*5*).

The second issue is that growing demands for clear accountability for the expenditure of Federal funds may conflict with the need for greater flexibility at the State level. The determination of Congress and the Federal agencies to monitor and control program funds more closely is predictable in an era of fiscal restraint. Symptomatic of this trend is an increasing Congressional tendency to subject all programs to the annual appropriation process, to "sunset" programs at defined intervals, and to seek the right to review all regulations promulgated by executive branch agencies in carrying out legislative intent. Likewise, DHHS and other Federal agencies have increased accountability procedures, audits to detect fraud and abuse, and independent program evaluations to measure the fulfillment of programmatic objectives. Increase in Federal distrust and consequent attempts at control come at a time when the States themselves are having difficulty maintaining program effort because of inflation. Hence the States perceive that they are being given less, told to do more, and forced to tie up valuable time and resources in documenting their efforts for Federal authorities.

However it is also true that reporting on Title V, Medicaid/EPSDT and other programs has been lax in the past decade, resulting in an embarrassing lack of good information on the compliance of these programs with Federal legislative intent. Also, insufficient evaluative data currently exist on the performance of various programs at the State level. Such information is a minimal requisite basis for future policy determination, and must be available to the Congress, the Federal agencies, and the public.

The Panel acknowledges that it is difficult to increase both State autonomy and Federal accountability simultaneously. Several steps can be taken, however, that will serve both purposes. State administrative consolidations as noted above, and parallel Federal efforts as described in the next chapter, are valuable steps. Others include:

- *Federal accountability mechanisms which stress the Federal role in establishing broad performance objectives and standards, and the State role in demonstrating progress toward attainment of these.* The States should be granted wider latitude in devising means to attain the objectives.
- *Joint or concurrent applications and reporting forms for all Federal programs related to the health of children and pregnant women and joint or concurrent program applications where appropriate.* Precedent for this approach has been established by DHHS, within existing legislative authority, in a joint application process for various Federal primary care programs targeted to low-income families (*5*). Means should be sought, and where necessary legislation should be modified, to initiate demonstra-

tions in selected States of the consolidation of related funding streams to meet the needs of specified target populations (e.g., handicapped children). Such demonstrations would be initiated in response to State maternal and child health authority proposals and only authorized under reasonable and precise agreements for monitoring, outcome measurement, periodic reporting to Federal authorities, and contingency plans where program goals have not been met.

- *A new set of coordination criteria to be met by all new or continuing legislation relevant to the health of children and pregnant women,* requiring an introductory statement in the legislation itself of how the program or policy fits into the existing array of programs, how it is consistent with national goals, and how it does or does not conflict with other legislation; regulations and guidelines for each program also should show the steps taken to provide increased program coordination.
- *Interagency agreements to identify areas of responsibility, define specific steps to be taken, and assign realistic time frames for the realization of goals.* Such agreements between HCFA and Title V, between Head Start and HCFA, between Head Start and Title V, and between Title V and the Office of Special Education and Rehabilitation Services have shown promise of mutually increasing program effectiveness.

The Joint Funding Simplification Act of 1974 would alleviate many accounting, reporting, and auditing problems, but this statute is permissive rather than mandatory. As a result, practically nothing has been accomplished under it. Either broader legislation that focuses on the essential requirements of coordinating services to individuals, such as eligibility simplification, or a specific mandate to provide coordination for maternal and child services is needed.

The Role of Title V

Before turning to issues in local service coodination, the Panel wishes to comment in more detail on the Title V program that is at the heart of so many of the State-Federal governance issues taken up in this section. Although we have argued that a broad range of private and public efforts will be required to meet the national objectives we propose, it is evident that much of the initiative for advancing public health care programs for mothers and children has resided historically with the Title V program. Title V continues to be an essential "core" element in the national program portfolio, with great potential both as a vehicle for providing needed services and for increasing the coordination of all State and Federal programs relevant to the health of children and pregnant women.

Because the national objectives we outline do not amount to a radical departure from the original Title V objectives—but rather bring the original objectives up to date—we do not see the need to recommend any major new Federal legislation to unify national policy. Instead, we adopt an incrementalist frame of reference and recommend that Title V be revised, according to the specifications detailed in volume II of this report, in order to provide the leadership and pivotal policy focus required to move ahead.

One of the Panel's chief recommendations is that Congress substantially increase the appropriation for Title V and that States provide the required matching funds. Increased funding is essential because the revamped Title V program proposed here involves major new management functions and new service objectives for the program. Funds will be necessary to elicit additional State support, strengthen State staff, promote better program coordination, and extend services to those most in need when no other funding sources are available. In particular, we believe that modest increased investment via Title V can result in significant multiplier effects and long-term economies in the implementation of all public policies and programs surrounding pregnancy and the early years of life (family planning, EPSDT, WIC, regional perinatal care, and others) and the care of physically and mentally handicapped children (Medicaid, SSI, Developmental Disabilities, P.L. 94–142, child mental health programs, and others). These are two of the largest areas of present national policy commitment, and two of the areas where well-coordinated policies can make a demonstrable difference. The success of Title V modifications will depend in significant measure on the full implementation of the previously stated recommendations regarding performance criteria and improved accountability.

Local Service Coordination

Improved coordination is often proposed as a quick and simple way to maximize and redistribute existing resources. However, the truth is that the word and the concept "coordination" have in the past carried very little substance. With at least three levels of government, as well as a multitude of private community organizations, coordination is extremely difficult and becomes less formal and bureaucratic as one approaches the community level. It is here that cooperation among jurisdictions and among professionals involved, as well as community involvement and pressure, are translated into meaningful action. Making the health system work for all children and pregnant women is a difficult enough task. When, as is essential, it must be linked with other equally complex service systems in the fields of social services, education, corrections, and rehabilitation, the difficulties are enormous. This is not to say coordination of resources and service delivery responsive to the individual needs of children and mothers is impossible; only that it is hard to do, requires structures and systems covering the entire array of resources and services, and must be backed by the power to assure that comprehensive plans are carried out as intended.

Although there are no magic formulas for improving coordination, administrative considerations in the improvement of health services have received much attention among public officials in the past several years, and certain approaches have been demonstrably successful in more than one community. Steps that have alleviated the coordination problem include the following:

- Collocation of services—e.g., an adolescent health clinic within a high school
- Single point of administration—control of public health clinic budget, school health budget, and WIC program in a single office
- Staff consolidation—pediatric staff at a local teaching hospital also rotate through community primary care clinics
- Common rules and procedures—joint eligibility determination for AFDC and WIC services
- Single point of service access—a comprehensive health center, where initial application serves for entry into health, mental health, dental, nutritional, and social services
- Common outreach and access services—home health visitors
- Compatible information bases—compatible forms for EPSDT and school health screening
- Various techniques of case management and advocacy—a "lead" agency coordinating care for all children with a particular handicapping condition (*6*)

These approaches, and variations on them, offer an extensive repertoire of ways to improve the coordination of services at the local level.

Obviously, local attempts to standardize or simplify regulations and procedures across program lines often are constrained by Federal and State requirements. Special problems in the use of Federal and State program funds are created by conflicting eligiblity criteria, inconsistent definitions of income and assets, conflicting rules regarding "first dollar in," incompatible procedures for assuring confidentiality, differing diagnostic categories, and incongruent service districts. Even communities that have made major strides toward better coordination have been forced at times to choose partial solutions pending resolution of such inconsistencies at the State and Federal levels (*7*). Some even have turned down Federal or State funding because rules governing the use of funds seemed to bring more problems than the money itself would solve (*8*).

Although establishing a single point of service administration has been among the more difficult reforms to achieve, several cities with sizable low-income populations—Denver, Colorado, and Cambridge, Massachusetts, for example—have managed to completely restructure and consolidate public primary care so that a single system of peripheral neighborhood clinics now offers excellent unified care, with the clinics fully linked to a municipal hospital (*9, 10*). The systems evolved somewhat differently, reflecting a complex interaction of local political, administrative, and leadership factors. But they have in common a substantially integrated control of all Federal, State, and local child health budgets under one agency or administration. Places where such systems have worked have benefited from timely creation of new health and hospital agencies, good relations between the health agency and local elected officials, public health department leadership, a cooperative and complementary private practice sector, and major involvement of hospital-based physicians and administrators. The availability of funds for comprehensive health centers and other Federal programs also has been a large factor in service coordination (*11*). *These are models which, though difficult to replicate exactly, would lend themselves to imitation by many other municipal governments.* Their proven cost effectiveness should offer some incentive for local policymakers throughout the Nation to follow suit.

Less ambitious, though also deserving of national attention, are various models of case management and case advocacy. Case management is based on the assumption that in many areas it is more efficient or feasible to help patients establish appropriate patterns of use and take advantage of existing services than to restructure agency effort. Case advocacy has proven very successful in helping parents of some Head Start children. A recent GAO report documents the cost effectiveness of the Child and Family Resource Center Program, which offers comprehensive family-oriented consultation in addition to traditional Head Start services (*12*). Case management also has worked in many communities where a lead agency has been assigned responsibility for care of children with specific handicapping conditions.

The need for improved systems of case management has grown with the advent of P.L. 94–142 in the schools and other programs which mandate that a responsible agency determine the child's needs and then evolve and carry out an individualized plan for meeting them. The plan frequently requires the involvement of multiple service providers. Rather than rely on the family to locate and coordinate the necessary services, an individual in the responsible agency should make the contacts, explain the problems and the services needed, and assist the family in obtaining the services. Too often, however, the plan is only a piece of paper listing needed services and the family must depend on its own resources to find and coordinate them. Also, children sometimes are subject to several such individual plans at once, with conflicts and confusion arising as a consequence (see chapter 8).

As long as active and well-coordinated case management accompanies individual care plans, the Panel believes the plans are a very good instrument for service coordination. *In general, case management is a relatively inexpensive service which can maximize the impact of more expensive services. As such it should be an allowable cost of appropriate agencies and programs.*

In general, the Panel believes that aggressive coordination of public programs, and of private and public efforts, remains essential for every community. Although we believe the States should monitor public programs to be sure that needed services are delivered and standards upheld, we also recognize that only at the local and county level can the needs of children and their families actually be met. Moreover, local initiative and community action cannot be induced by Federal and State authorities—they must result from the work of many interested and able people working toward common goals.

Parallel to our recommendations regarding Federal and State responsibilities, *we therefore believe minimal community responsibilities should be to:*

(1) Assign a lead agency or publicly appointed body to assess whether the existing network of private and public health care

arrangements is sufficient to meet the primary care needs of all children and pregnant women; whether children with special needs are being identified and treated adequately; and, whether prevention and promotion activities are widely available in the schools and in neighborhoods as well as in health care arrangements.

(2) Charge this same agency or publicly appointed body with publicizing these findings; participating in regional and State planning efforts according to common Federal-State planning requirements; and exercising leadership in community actions to improve existing services.

(3) Contribute local tax dollars, both as a match for State and Federal monies and independently, to achieve major health objectives for children and pregnant women.

(4) Take necessary steps to increase coordination among providers of health and health-related services, along the lines discussed above.

For lead agencies to carry out these roles effectively, they will need adequate staff resources.

HARNESSING BROADER POLICY MECHANISMS

In addition to consolidation of management and program coordination, six broad policy functions should be better harnessed at the local, State, and Federal levels in the future as mechanisms for attaining the major health objectives for mothers and children, and for assuring that the various Federal and State programs relevant to health care for mothers and children—including handicapped children—are implemented in a mutually reinforcing and efficiently targeted fashion. These functions include planning, quality assurance, development of information systems, demonstrations, technical assistance-consultation, and advocacy.

Planning

The most rational method for deciding how to deliver essential services is to plan. Service planning is a cycle that begins with statement of objectives, continues through needs assessment and an inventory of resources, establishes priorities among needs, considers and chooses among service delivery options, and follows through after program implementation with evaluation to generate information for a next phase of policy development.

Two major problems exist in maternal and child health planning. First, the complete planning cycle is rarely carried out at any level of government or integrated properly with budget and policy determination. Second, multiple programs and policies have generated separate planning requirements, usually for different purposes or aspects of decisionmaking and frequently not focusing adequately on the needs of children and pregnant women. The result is considerable confusion about the entire planning process and its usefulness for moving toward attainment of national objectives.

The Panel believes several steps can be taken at the State and Federal levels to help. First, *State agencies administering Title V funds and related program dollars should contribute more significantly to the planning process for all programs offering health and health-related services to children and pregnant women. This should be done both by establishing clear and simple planning requirements for the Title V program itself, and by giving the relevant State unit an enlarged role in broader State health planning efforts.*

Although the Title V statute makes the approval of a State plan for maternal and child health services and services for crippled children a condition for receiving funds, most State plans consist only of program descriptions with notes about what could be accomplished with additional funding, plus a compendium of reference documents required by Federal regulation. The State Title V plan in most cases does not reflect population-based needs assessment, plans for implementing change, coordination of effort with other programs and agencies, or a process which allows for significant involvement of providers or consumers—since none is currently required by Federal regulation.

The inadequacy of State planning for children and pregnant women also results from the equation of maternal and child health services with the Title V program, and the consequent failure to integrate the services delivered or funded by other agencies, or provided through the private sector, into a comprehensive plan. An adequate plan also must contain an analysis of State resources and strategies for coordination of effort with other agencies controlling relevant Federal program funds such as Medicaid, Community Health Centers, and Title XX. As one mechanism for strengthening State planning, the Panel recommends revision of Title V planning requirements to mandate a much broader State planning process that recurrently evaluates the health needs of women and children in the State (particularly those of low income or minority status and with special needs), describes the full range of health and health-related services they are receiving, and assesses selected health outcomes. The planning requirement should also be designed with the understanding that Title V monies are to be used in combination with many other sources of Federal, State, and local revenue.

Another planning problem can be traced to relatively new Federal legislation. The National Health Planning and Development Act (P.L. 93–641) gave State Health Planning and Developmental Agencies (SHPDA's) and area Health Systems Agencies (HSA's) responsibility for planning designed to improve the health of persons within States and geographic subdivisions of States. This planning mandate, intended to ensure access to needed health services and to restrain the rising costs of care, was superimposed upon an already complex process in most States by which the governor, the legislature, and regional Federal authorities determined health care priorities. While the long-term effect of the new legislation may be to enhance development of maternal and child health services, its short-term consequence has been to generate confusion about which planning process should be taken seriously. Title V agencies have not usually been involved in the new State and local health planning processes and have found themselves planning only for the limited Title V programs under their direct control, while the new planning entities have tended to focus on institutional care, care for the elderly, and other high-cost sectors because of concern for cost containment. Both trends have resulted in most parts of the country in low visibility for and insufficient attention to comprehensive care needs of mothers and children, despite the increase in Federal and State programs for these groups and the importance of rational effort on their behalf.

The Panel believes that effective planning in maternal and child health for the coming decade will depend on strengthening and better coordinating the various mandated planning processes. Specifically, we recommend that:

(1) *The State maternal and child health authority responsible for public health services to children and pregnant women should share with the HSA's, SHPDA's, and State Health Coordinating Councils (SHCC's), the overall responsibility for maternal and child health planning.* Collaboration between this authority and the federally mandated planning groups should produce a document with the following characteristics:

- It should (a) identify and order the unmet health needs of mothers and children; (b) identify available resources and the ability of these resources to meet unmet needs; (c) set specific and measurable goals for improving services and health outcomes; (d) specify steps to be undertaken in attaining these goals; and (e) specify steps to coordinate efforts among local providers in attaining these goals.
- It should assess the extent to which relevant federally supported programs, such as maternal and child health clinics, WIC providers, EPSDT providers, family planning clinics, and programs for handicapped children, are meeting national objectives in their areas, and are working jointly toward these objectives.
- It should be designed so as to be used wholly or in part for four purposes: multiyear planning within the agency unit itself; the maternal and child health component of the State Health Plan; the State maternal and child health plan required in order to receive Title V funds; and as a basis for Health Planning Agency "appropriateness reviews" regarding use of Federal funds.

Although the specifics of the planning process undoubtedly will vary from State to State, each State as a minimum will need to assemble data on a small area basis—such as health systems' areas or counties—about the health status of mothers and children, the public and private resources available to provide the necessary services described in this report, and the patterns of utilization of existing services.

(2) *The HSA's, SHPDA's, and the National Health Planning Council need direction and guidance to become more effective in planning and allocating resources for the promotion of health*

among children and pregnant women. Specific steps should include:

- Specification by the Secretary of Health and Human Services of maternal and child health as a national health priority. The National Guidelines for Health Planning contain a few relevant goals for children's health promotion, for example, immunizations for children under 15. More specific children's health promotion goals are needed to provide guidance to the HSA's and SHPDA's. These should place emphasis on assuring access to three basic essential services—prenatal, delivery, and postnatal care; comprehensive care for children through age 5; and family planning services.
- Requirement that HSA's coordinate closely with State maternal and child health authorities in regard to the HSA functions of (a) review and comment on requests for Federal funding of maternal and child health services; (b) approval of Proposed Use of Federal Funds (PUFF) in relevant programs; and (c) appropriateness reviews. HSA boards should have adequate representation of persons with expertise in maternal and child health, and State maternal and child health authorities should assign personnel to participate in HSA meetings at which relevant matters are to be considered.

(3) *The Federal maternal and child health agency, described in the next chapter of this report, should work with the National Council on Health Planning and the Bureau of Health Planning in the development of the materials necessary for effective relationships between State maternal and child health authorities and State planning agencies.* These would include:

- Instructions to HSA's, SHPDA's, and SHCC's concerning the maternal and child health section of the State Health Plan.
- Information to help HSA's understand the implications for women and children of decisions made on Certificates of Need, Proposed Use of Federal Funds, and Appropriateness Reviews.
- Manuals to explain the scope of maternal and child health services and the responsibilities of State maternal and child health authorities to SHPDA and HSA boards and staffs, and also the terminology and techniques used by the health planning agencies to the State maternal and child health authorities. The National Institute of Mental Health already has prepared such a manual for community mental health centers and HSA personnel.

These steps, if taken jointly, would reduce existing confusion and reverse the present trend for maternal and child health planning to "fall through the cracks" of the State planning process. The Panel believes such planning is an important HSA function, and significantly more in keeping with the original purpose of the health systems planning legislation than the more narrow issue of cost containment that has consumed so much energy recently.

Quality Assurance

Assuring the ready availability of essential services will be of limited value unless the quality of those services is high enough to have a major impact on the health of mothers and children. The Panel therefore believes the process of quality assurance, including establishment of standards and monitoring of performance, must also be employed in pursuing national objectives.

The Title V legislation and regulations require States to assume responsibility for various quality assurance functions, and to develop and upgrade standards relating to services. State Title V agencies are perhaps best known for quality assurance regarding crippled children's services. Since its inception the Crippled Children's Services program has assured its beneficiaries appropriate services of high quality. This has been accomplished by establishing standards that go beyond professional licensure or institutional accreditation for payment of specified services. Crippled Children's programs often require providers to have specialty board certification for payment, or specify that certain procedures can be performed only in institutions which meet standards relevant to that procedure. When the Maternal and Infant Care and Children and Youth projects were initiated, they were made subject to similar high standards of staffing and procedure. Consequently, when studies compared the quality of care in these facilities to that of clinics in teaching hospitals, private providers, and others, the Title V-funded projects scored very high (*13*).

The Panel recommends that Federal and State maternal and child health authorities continue and expand their activities in the realm of quality assurance. It should be the responsibility of the Federal maternal and child health authority to establish minimum national standards for personnel, facilities, and delivery of care. The process for standard-setting should be broadly representative, including input from physicians, other health professionals, consumer representatives, and others. It should continue to be undertaken in collaboration with the relevant professional and institutional groups, such as the American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American Medical Association, American Public Health Association, American Nurses' Association, and the Joint Commission on the Accreditation of Hospitals. In addition, exceptions to federally established standards should be allowed when the State maternal and child health authority or the facility being reviewed can provide adequate justification, such as the inability to obtain personnel with certain credentials in isolated areas or the irrelevance of the stipulated criteria to specific circumstances. The Federal agency should also establish minimum expectations for the monitoring of performance: how often records should be reviewed, who should conduct the audit, how large a sample is required, when procedures other than record reviews are essential, and so forth.

Just as the Panel believes that State maternal and child health authorities should ensure the availability of services by working collaboratively with service providers not funded by Title V, it also believes that these authorities should monitor the quality of services provided to mothers and children by public agencies other than those supported by Title V, requiring that they conform to the same standards as those expected of Title V facilities and monitoring compliance with those standards. Waivers might be sought by some facilities, such as migrant health centers in isolated areas, but such waivers might also be required by Title V-funded local health department clinics in similarly isolated circumstances, so no dual standard of care based on source of funding should be maintained.

The main objective of the State maternal and child health authority should not be to detect deficiencies, but rather to prevent them and continually upgrade services. The Panel believes the right to monitor program quality carries with it the obligation to involve the monitored program in the promulgation of standards and to work with the program in training personnel, making all modifications necessary to conform with standards, and consulting frequently on program development. The enforcement of quality assurance in programs not funded by Title V will require collaborative agreements at the local, State and Federal levels between maternal and child health authorities and the agencies funding other programs.

Just as in the case of planning, quality assurance presents some difficult issues of coordination at the State level. In particular, there is the potential for confusion between the maternal and child health quality assurance process and the activities of the Professional Standards Review Organizations (PSRO's), the HSA's, and the State Medicaid agency. The Panel believes that the intersection of various quality control activities needs to be studied State-by-State, with more thought given by both State and Federal authorities to mutually reinforcing policies.

Information Systems

In the age of the computer, it is possible to generate enormous quantities of data on target populations and services. A more elusive goal, however, is to collect only that information which will actually be *used* cost effectively in policy determination and review and program improvement. The Panel does not advocate wholesale increase in data collection or analysis. Instead *we recommend that each State develop a carefully reasoned strategy for collecting and using three types of information: policy-related epidemiological data on health status and health care access, management systems data on receipt of services and use of funds, and evaluation data on program effectiveness based on stated objectives and specific goals.* Each of these types of information can be analyzed and presented in a number of ways to meet different policy needs including accountability to Federal agencies, State planning, and internal agency administration.

Policy-related epidemiological data is population-based information on health care needs and access to health services. Such data can be very selective, focusing on high-risk problems or populations in the interest of developing better targeting strategies. The data can be collected intermittently or can be part of an ongoing surveillance strategy aimed at assessing progress toward high-priority health service goals. One good example of targeted data collection is the Georgia system of perinatal surveillance (*14, 15*), which includes a sampling of birth and death certificates to establish the neonatal mortality rate for selected areas and according to various maternal characteristics. These data are analyzed to devise service targeting strategies, and are also disseminated to relevant service providers and administrators. Similar systems have worked for immunizations, and can be envisioned for childhood accidents and other major problems. Surveillance information also can be used as one form of outcome measurement to determine population changes on important health status indicators. Although such changes may or may not be attributable to the health service system, Federal and State authorities should weigh this type of outcome data along with data on receipt of services as one important measure of progress toward the achievement of performance objectives.

In general, targeting of services based on problem-oriented surveys is easier and less expensive than attempting to create and maintain risk registries, or otherwise identify and track individual children and mothers over time. The Crippled Children's Services program attempted, particularly in its early years, to set up registries, but these listings were rarely used and proved ineffective in making sure that needy children received treatment. Two exceptions can be found, however, to the generally discouraging record of risk registries. One is the recent experience in this country with child abuse registries, which have been part of a broad new child abuse reporting system. The other is the promising development of systems for identifying and tracking high-risk pregnancies during the interval from the earliest prenatal visits to the return of the mother and infant to the home after delivery. A number of perinatal care networks have experienced notable success in developing such systems.

In most States, even those with relatively sophisticated human services accounting, policy-relevant management information on the delivery of maternal and child health services is minimal. This absence of information in many States can be traced in part to the 1976 decision to disband the Federal Maternal and Child Health and Crippled Children's reporting systems. Reduction in Federal expectations has led to laxity in some States, even though State authorities usually recognize that it is in their interest to have good information on needs and program performance. Another reason for the inadequacy of State data systems is simple lack of money for planning, either as part of the Title V process or for other State efforts.

Reporting systems have been a cause of major concern in Congress, but for the most part the concern has been about fiscal accountability, not service accountability. Information systems such as the Medicaid Management Information System are designed to remedy problems such as fraud and abuse, that is, overutilization, not underutilization.

Since 1969, the EPSDT program of Medicaid has been charged with identifying children eligible for services and seeing that services are provided. Eligibles are identified, not on the basis of risk, but according to the financial and categorical criteria of the welfare-based Medicaid program. The fact that welfare and social service departments have case files on all families eligible for Aid to Families with Dependent Children should make identification easy. However, many States have had severe problems in setting up computer systems that could identify eligible children and report on those who needed care. Those States which have been most successful are those which from the outset had strong computerized data bases and a capacity in both health and welfare departments to function effectively (*16*).

Problems can be compounded when various programs develop parallel and incompatible data bases to meet Federal accountability criteria. In general, the most useful human services information systems have been those which established common language and categories across programs, enabling integration of data bases at the stage of analysis.

As well as designing better information systems relevant to management, monitoring, and accountability, the Panel believes that States should further develop their own capability for program evaluation. This function should be undertaken within the maternal and child health authority and, as in the case of several large States, may also be undertaken by staff attached to the State legislature, the State management and budget agency, or State auditing staff. California, New York, and several other States now have such capabilities. The reports produced are in many cases as sophisticated as Federal reports of the Congressional Budget Office, Office of Management and Budget, or General Accounting Office. Evaluation efforts should focus on how well and how efficiently national objectives are being attained, and on the congruence among various Federal, State, and local programs in working toward common ends.

Demonstration Programs

The Panel believes that Federal and State demonstration programs should continue to support models of exemplary practice in service delivery. It is apparent, however, that inflation and the increased cost of providing health services has meant that an ever-larger component of State funding has been required to maintain levels of effort in existing demonstration projects, and that almost no State presently has sufficient funds to contemplate new demonstrations.

This would not pose a dilemma if current programs had proven unsuccessful and deserved to be disbanded. However, in the case of the MIC, C&Y, and other demonstrations under Title V authority, as well as various demonstrations under Medicaid, WIC, community health centers, and other Federal and State programs, notable success has been achieved and highly cost-effective services provided.

We believe it makes sense to maintain and further spread these successes before creating new service delivery demonstrations. We also believe, however, that new funds are necessary to support demonstrations of (1) more efficient service structures at the local level; (2) new modes of coordination between various Federal and State programs and funding streams with related objectives; and (3) the provision of certain services which would in themselves perform a coordinating function (e.g., home *visiting).* The previous generation of demonstrations has shown that comprehensive services can be provided in cost-effective ways. What has not yet been adequately shown is how to unify the implementation on a large scale—beyond an individual service structure—of various closely related policies and programs. Support for this kind of innovation is not likely to come from existing program funds alone.

Technical Assistance and Consultation

Another important aspect of knowledge transfer, along with demonstrations, is technical assistance and consultation—the process of familiarizing providers, professional groups, and other communities of interest with the best ways to achieve desired ends. In a world of rapidly changing health care knowledge and practice, providers need information and support of many kinds. Similarly, in the busy day-to-day world of public policy, no Federal or State agency performs well which does not explain its purposes clearly, engage in open and frequent exchange with various client groups of providers and consumers, and offer them timely and informed assistance in working toward shared objectives. Strong patterns of technical assistance and consultation require excellent agency staff, and enough staff to communicate fully and carefully. While neither Federal nor State agencies presently have enough staff to perform these functions adequately, it is the Panel's impression that the States have the biggest problem.

The Panel believes that Federal policy should try to build an intelligent and energetic cadre of professionals within each State who would work for the relevant State health unit to communicate program goals and translate national objectives into realities of local practice. Some of these professionals should be full-time public servants, but some also should be drawn from universities and other settings on a contract basis, in order to broaden the range of qualified and interested personnel who can participate.

Advocacy

Advocacy can be of at least two kinds, that which comes from within public programs and units of service administration, and that which comes from private groups and individuals. Both are important to advance the scope and quality of services for children and pregnant women (*17*). For reasons described in the brief historical section earlier in this chapter, public agency advocacy has become more diffuse and less prominent in recent years. The Panel hopes that with the integration of program policy and oversight at the Federal, State, and local levels, and the various other reforms we have proposed, agency advocacy will be rekindled. No maternal and child health unit can influence the allocation of scarce public service resources—some of them not under its direct control—without strong ties to various communities of interest and the ability to make persuasive arguments for the priority of its goals.

In reviewing recent achievements of certain outstanding Federal, State, and local agencies, it is difficult to escape the conclusion that many of the most impressive steps have been the result of forceful leadership by particular individuals, who somehow have been recruited to the cause of maternal and child health and have made it their mission over a number of years to ensure that agencies and programs thrive. If there were a surefire formula to motivate others like them, the Panel certainly would recommend it. In the absence of such a formula, *we believe that adequate financial and professional incentives need to be created, from both private and public sources, to attract highly qualified and motivated individuals to relevant public service roles.*

In addition, *we believe that Federal and State policy advocacy can be significantly improved by the creation of interagency maternal and child health advisory councils, to lend visiblity and unified purpose to the efforts of all relevant agencies.* A Federal council of this sort is proposed in the chapter which follows. State councils should be appointed by the governors, or appointment power should be delegated by the governors to health department directors. The councils should include representatives of the relevant agencies and professional groups, and consumers knowledgeable about maternal and child health, with appropriate racial and ethnic balance. The councils should fulfill such duties as approving the maternal and child health component of the State Health Plan, and other plans as required; overseeing State quality assurance efforts; providing advocacy with the governor; legislature, and other policymakers for more effective programs and policies; and initiating periodic reviews of particular aspects of State programming and policy.

These functions should serve to reinforce and extend various agency activities. The council should serve primarily as a coalition to support and assist the State maternal and child health program director and other agency personnel in ongoing program and policy formation, not as a vehicle for political control of these personnel.

Even with the most sophisticated and committed child advocates working inside Government, the Panel believes advocacy by organizations and individuals independent of Government is indispensable in achieving its goals for mothers and children.

The neglect of children's interests by the present system has taken several forms which advocacy efforts must be designed to redress and to prevent in the future. First are decisions made by legislatures and governmental bodies which are unresponsive to children's needs not by intent but out of ignorance. The Panel is aware of many instances in which well-meaning public officials set policy without understanding its particular implications for the health of children and expectant mothers. Thus, for example, when HCFA wrote policy in 1978 to implement the new Rural Health Clinic Services Act of Medicaid, it issued a regulation requiring that in order for a clinic to qualify for Federal reimbursement under the program it must serve people of all ages. An unintended consequence was that maternal and child health clinics could not qualify for Federal assistance even if they were located in rural areas and provided services to some of the neediest people the program intended to help. It was only through the work of outside advocates that the problem was identified and that HCFA was convinced to modify the policy.

A second form of neglect which the Panel believes outside advocacy can help address is the low priority frequently given children's needs in negotiations at all levels of government over budgets, staffing, and other important programmatic decisions. Because many of the services children need are neither particularly expensive nor dramatic and because a vocal outside constituency has frequently been lacking, children's needs have too often taken a back seat in these crucial deliberations. In many States, children's programs are particularly poorly funded and are among the most vulnerable when budget or staffing cuts are made. In others, children go without services which existing programs entitle them to because the programs are not being administered as effectively as they might be.

A third broad area where outside advocacy can play a vital role is in harnessing resources in the private sector on behalf of children's needs. Provisions made by industry regarding maternity and paternity leave or leave for parents with sick children can affect children's lives profoundly, as can the willingness of private providers to offer the range of services children need, of labor and management to purchase adequate coverage for their employees and dependents, and private fund-raising efforts like the United Way to accord priority to maternal and child health needs. As with advocacy aimed at the public sector, outside advocacy aimed at these private sector activities is necessary to assure that appropriate resources and talents are focused on the health of children and expectant mothers.

The need for outside child advocacy is particularly acute at times like the present when there is public skepticism about the ability of Government to have a positive impact on people's lives and pronounced pressure to reduce Government's authority and funds.

The Panel believes that child health advocates are indispensable allies to government officials, to parents, and to others concerned with harnessing both public and private resources on behalf of improved maternal and child health. *We therefore recommend substantially increased levels of support for advocacy from a range of sources in the private sector, including private and corporate foundations, corporate contributions, contributions from individuals, and private fund-raising campaigns.*

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CHAPTER 11

FEDERAL ADMINISTRATIVE ARRANGEMENTS

The Congress specifically asked the Panel for advice about "appropriate methods for coordinating and consolidating, within an agency and between agencies, the administration of child health promotion programs." This request stemmed in part from a widely shared perception within Congress, the Executive Branch, and the broader child health community that the many federally sponsored programs relating to maternal and child health too often function in isolation. One hears often of fragmentation, duplication, and lack of coordination, both at the Federal level and at the State and local levels, where administrators working with more than one program must frequently deal with different eligibility standards, regulations, and reporting forms; and families face a complex and bewildering array of health service programs that they must piece together to meet their needs. Although this is a problem in many sectors that rely on Federal funds, it is especially burdensome in the child health arena, given the objective of continuous, comprehensive care.

In the previous chapter, we suggest a number of ways to clarify and in some instances restructure State-Federal relationships in the administration of various maternal and child health programs. In this section we propose several changes at the Federal level to enhance the ability of programs at the State and local levels to accomplish their goals; and, more generally, to enable the Government to attain the numerous policy objectives described throughout this report and detailed in volume II. The Federal level changes proposed by the Panel include:

- Creation of a Maternal and Child Health Administration (MCHA) as a new agency of the Public Health Service (PHS)
- Steps toward a new relationship between PHS and the Health Care Financing Administration (HCFA)
- Creation of a National Commission on Maternal and Child Health
- Identification by the Secretary of the Department of Health and Human Services (DHHS) of a person to be responsible, as the agent of the Secretary, for coordinating maternal and child health policies both inter- and intradepartmentally
- Increased congressional attention to improving the coordination of programs that are the responsibility of different committees.

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- Strengthened expertise in maternal and child health in the regional offices of DHHS

These suggestions are grounded in several assumptions. First, the Panel recognizes that people and their values, far more than organizational structures, are the critical variable in program coordination and success. Energetic and competent leaders within DHHS and in other departments, backed by strong staffs and functioning with the full support of a committed DHHS Secretary in particular, are likely to achieve more for maternal and child health than any administrative rearrangements, although such realignments may facilitate the actions of a committed leadership. Second, the Panel recognizes that the current plethora of programs in the maternal and child area exists not through carelessness or misguided management. Rather, it accurately reflects multiple policy objectives, congressional jurisdictions, the styles and preferences of leading administrators within DHHS, political priorities of past years, and the pressures and interests of selected constituencies. Moreover, a focus on maternal and child health in numerous Federal programs, departments, and agencies reflects as much the importance of this issue as it does "fragmentation and duplication." That is, if a topic is of national importance—as is the health of our mothers and children—it is logical and even desirable that programs addressing it be found in many places. The Panel recognizes and celebrates the value of some diversity of effort.

Finally, we are keenly aware of the disruption and lack of success that typically accompany major organizational shifts undertaken in the absence of clear cut policy objectives. Organization—and therefore reorganization—must derive directly from new policy commitments and widely shared perceptions of problems. Thus, the suggestions for organizational change outlined in this chapter are viewed as necessary steps toward the major new policy directions recommended throughout this report, and as appropriate responses to many of the difficult issues and social trends identified in the course of our work. Some of the policy directions and problems which provide the underlying rationale for the Panel's suggested administrative changes we suggest include:

- The Panel's call for an aggressive national commitment to protecting and promoting the health of mothers and children
- The proposition that a core set of basic, essential services for women, infants, and preschool children becomes universally available without delay
- The expanded role proposed for the Title V program, which includes a significant new set of responsibilities for maternal and child health authorities at the State level
- The Panel's proposals to change various financing systems to extend and improve health services for mothers and children
- The need for more advocacy for the special health service needs of mothers and children, particularly in light of expected demographic trends over the next several decades
- The need for a clear focal point within DHHS for the various advocacy and constituency groups concerned with improving maternal and child health

The Panel believes that for these new policy directions to be implemented most effectively and forcefully, is it essential that the administrative changes argued for here occur. Whatever temporary dislocations may be caused by these changes are more than justified by the anticipated result—improved health status and health services for mothers and children.

A MATERNAL AND CHILD HEALTH ADMINISTRATION

In reviewing DHHS administrative arrangements governing maternal and child health programs, the Panel noted a central organization problem that it believes significantly hampers the ability of the Federal Government to care for the health needs of this population: at present, there is no clear departmental "home" within DHHS for maternal and child health. Programs related to the health needs of this population are found in several parts of the department with insufficient coordination and communication among them. For example, the adolescent pregnancy care and prevention activities authorized by P.L. 95–626 are located in the Office of Adolescent Pregnancy Programs (OAPP) within the Office of the Assistant Secretary for Health—quite separate from the obviously complementary activities of the Office of Maternal and Child Health within the Health Services Administration. This lack of a central focus is worsened by the low position in the bureaucracy of most maternal and child health programs, especially the Title V program which is within an Office within a Bureau, within an administration, which itself is only one of six PHS agencies. The Panel believes that this combination of fragmentation and "low profile" for maternal and child health programs results in a lack of clear policy direction, and insufficient support, advocacy, and visibility for the relevant programs. We have concluded that an organizational entity at a bureaucratic level closer to the Assistant Secretary for Health and the department Secretary, and focused on the preventive, primary care, and specialized health services required by mothers and children would greatly strengthen Federal health efforts on behalf of this population. Accordingly, *the Panel recommends that the Secretary of DHHS establish a Maternal and Child Health Administration (MCHA) as an agency of the Public Health Service.**

This Administration should include the following program components at a minimum:

- The existing Office of Maternal and Child Health, which administers Title V, Supplemental Security Income health services for disabled children, and programs directed at selected maternal and child health issues such as sudden infant death syndrome, genetic screening and services, sickle cell disease, and hemophilia
- The Office of Adolescent Pregnancy Programs, which administers the activities authorized by P.L. 95–626.

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*One panel member dissents from this recommendation. (See appendix D.)

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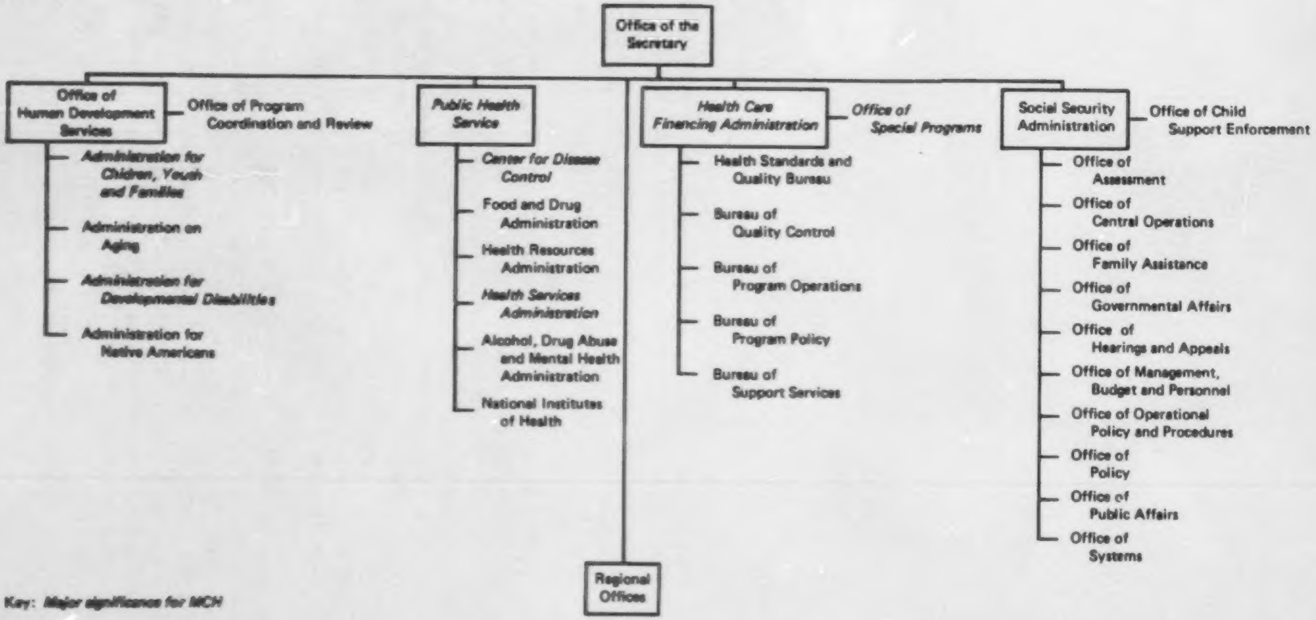
DEPARTMENT OF HEALTH AND HUMAN SERVICES


Office of the Secretary
Office of Human Development Services
Office of Program Coordination and Review
Administration for Children, Youth and Families
Administration on Aging
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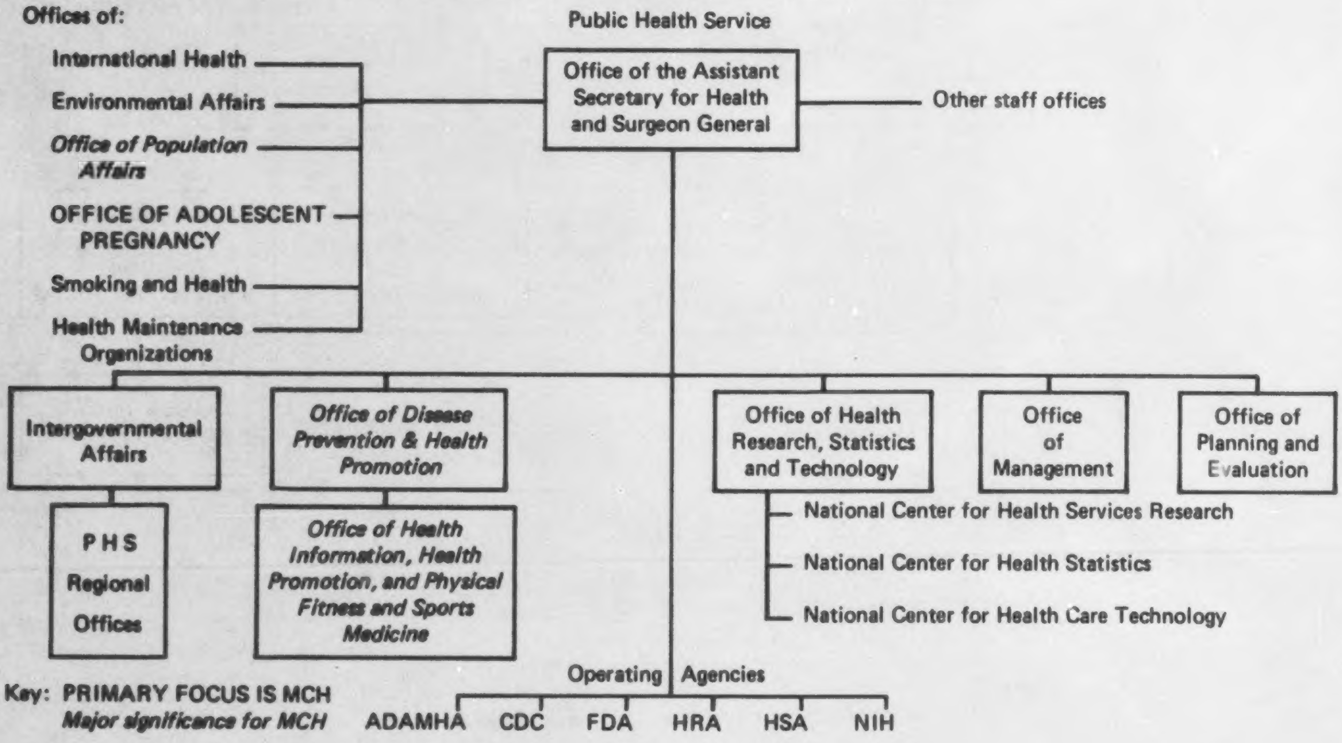
Administration for Native Americans
Public Health Service
Center for Disease Control
Food and Drug Administration
Health Resources Administration
Health Services Administration
Alcohol, Drug Abuse and Mental Health Administration
National Institutes of Health
Health Care Financing Administration
Office of Special Programs
Health Standards and Quality Bureau
Bureau of Quality Control
Bureau of Program Operations
Bureau of Program Policy
Bureau of Support Services
Social Security Administration
Office of Child Support Enforcement
Office of Assessment
Office of Central Operations
Office of Family Assistance
Office of Governmental Affairs
Office of Hearings and Appeals
Office of Management, Budget and Personnel
Office of Operational Policy and Procedures
Office of Policy
Office of Public Affairs
Office of Systems
Regional Offices

Key: *Major significance for MCH*

DEPARTMENT OF HEALTH AND HUMAN SERVICES


Offices of:
International Health
Environmental Affairs
Office of Population Affairs
OFFICE OF ADOLESCENT PREGNANCY
Smoking and Health
Health Maintenance Organizations
Public Health Service
Office of the Assistant Secretary for Health and Surgeon General
Other staff offices
Intergovernmental Affairs
PHS Regional Offices
Office of Disease Prevention & Health Promotion
Office of Health Information, Health Promotion, and Physical Fitness and Sports Medicine
Office of Health Research, Statistics and Technology
National Center for Health Services Research
National Center for Health Statistics
National Center for Health Care Technology
Office of Management
Office of Planning and Evaluation
Operating Agencies
ADAMHA
CDC
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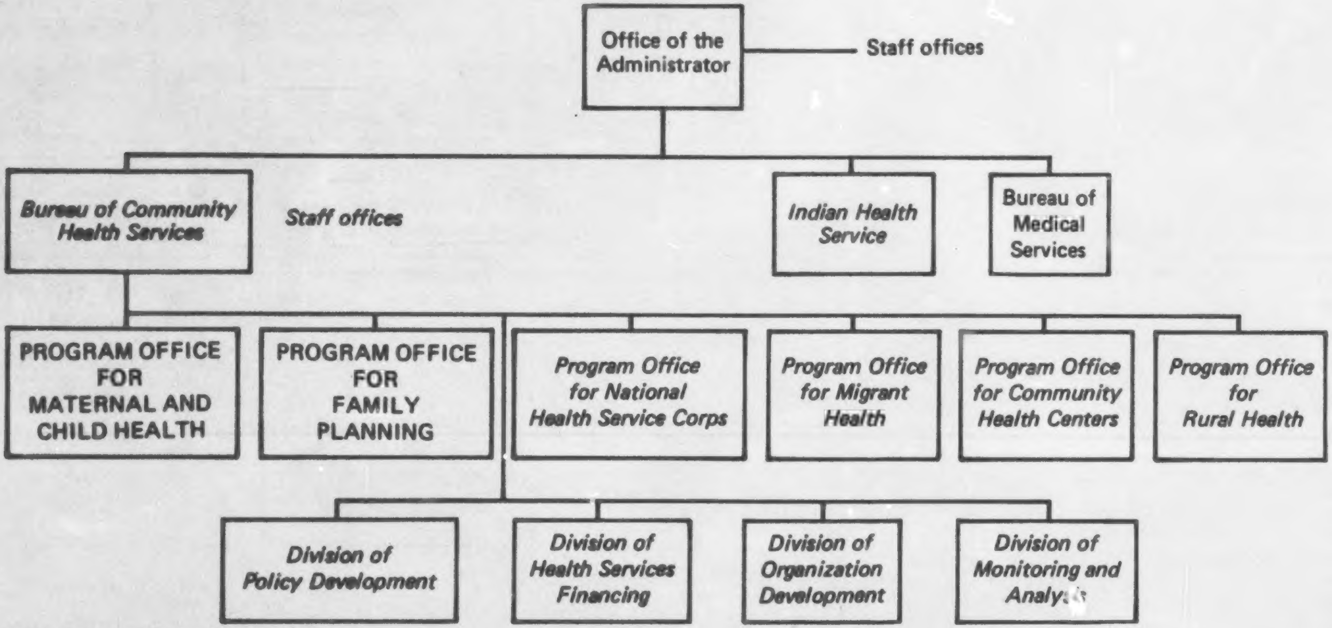
HSA
NIH

Key: **PRIMARY FOCUS IS MCH**
Major significance for MCH

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Services Administration


Office of the Administrator
Staff offices
Bureau of Community Health Services
Staff offices
Indian Health Service
Bureau of Medical Services
PROGRAM OFFICE FOR MATERNAL AND CHILD HEALTH
PROGRAM OFFICE FOR FAMILY PLANNING
Program Office for National Health Service Corps
Program Office for Migrant Health
Program Office for Community Health Centers
Program Office for Rural Health
Division of Policy Development
Division of Health Services Financing
Division of Organization Development
Division of Monitoring and Analysis

Key: PRIMARY FOCUS IS MCH
Major significance for MCH

- Family planning services supported through Title X of the Public Health Service Act.

The Maternal and Child Health Administration would function as the clearly designated leader for maternal and child health activities within DHHS. The following functions, at a minimum, should be assigned to the Maternal and Child Health Administration:

(1) Responsibility at the Federal level for operating and coordinating all aspects of the three programs listed previously including their service, research, and training components. In so doing, MCHA should not diminish the capacity of these programs—such as the sickle cell and adolescent pregnancy programs—to make direct Federal grants to community based organizations.

(2) Authority to review and comment on the proposed budgets, legislation, regulations, reporting forms, and other proposed policy issuances developed by other agencies within DHHS that conduct programs directly related to maternal and child health—with the aim of such activities being to improve program coordination at the local level in particular. Relevant programs include:
  - The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program of Medicaid and other Medicaid policies which affect large numbers of children or pregnant women
  - The Community and Migrant Health Centers Program of the Bureau of Community Health Services
  - Various other health service programs of PHS, including those of the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA)
  - Title XX (Social Services, including day care)
  - Head Start
  - The Developmental Disabilities program
  - Title IV, Aid to Families with Dependent Children
  - The National Institute of Child Health & Human Development
  - Selected programs within the Centers for Disease Control (CDC) including immunization, lead poisoning and veneral disease risk reduction
  - The maternal and child health activities of the Appalachian Regional Commission

  In discharging this review and comment function, MCHA should take into account the views of various departmental coordinating offices already in existence such as the Office of the Deputy Assistant Secretary for Population Affairs. We also note that there should be some reciprocity in the review and comment function noted here; that is, programs not included in MCHA such as those listed above should be able to review and comment on proposed regulations, reporting forms, and similar documents developed by MCHA which directly affect their programs.

(3) Assistance to the States on maternal and child health related topics, with the aim of creating and coordinating a system of services to ensure that all mothers and children have access to

needed services, especially those in the set of minimum, basic services. Such assistance should include provision of technical assistance to the States in the areas of planning, coordination, reporting procedures, and quality assurance; coordination with the Health Standards and Quality Bureau (within HCFA) to define in mutually acceptable ways the unique responsibility of State maternal and child health agencies and Professional Standards Review Organizations (PSRO's); and coordination with the health planning program to develop appropriate standards for State and multicounty health plans, and criteria for the "appropriateness" reviews and Proposed Use of Federal Funds reviews carried out under the Health Planning Act. (Chapter 10 discusses some of these State-oriented functions in detail.)

(4) Responsibility for setting national standards by which to assess the adequacy of the States' progress in ensuring the availability of the minimum set of basic essential services: prenatal, delivery and postnatal care; comprehensive care for children from birth through age 5; and family planning services. Such standards should be developed in conjunction with the National Health Planning Council and related planning bodies; the Board on Health Services Standards that we propose in chapter 5; the relevant professional societies, advocacy, and consumer groups; and other appropriate groups.

(5) Coordinating the maternal and child health programs of DHHS with related programs in other departments, such as the Supplemental Food Program for Women, Infants, and Children (WIC) within the Department of Agriculture, the Education for All Handicapped Children Act (P.L. 94-142) within the Department of Education, and the CHAMPUS program operated by the Department of Defense.

(6) Research needed to improve the agency's programs and to manage them effectively, which includes the ability to request and purchase needed research from other departmental agencies such as the National Center for Health Services Research.

(7) Advocacy within DHHS and directed to other departments and the Congress regarding policies and programs to improve maternal and child health.

With regard to locating the adolescent pregnancy program in MCHA, the Panel is aware that the Office of Adolescent Pregnancy Programs (OAPP) and the grant program it administers are concerned, among other things, with services such as vocational education and day care, which have not traditionally been considered a part of health services. There is some concern about whether such a multifaceted program belongs in a "health" agency such as MCHA. However, it is our intent that the concept of maternal and child health governing MCHA should embrace a very broad spectrum of services, as suggested by our needed services lists (chapter 5), and that therefore OAPP would easily fit within the new agency. We concur in particular with the orientation of OAPP that the services needed by these young people include, for example, specialized educational programs, counseling, day care, and other services—most of which are enumerated in the core and supplemental services incorporated in the description of the grant program in P.L. 95–626. To help ensure that these broader features of the program, as well as its prevention and coordination roles, are not lost in the shift to MCHA, the Panel suggests that the OAPP's status as a separate Office with its own director be maintained within MCHA. This will also help to continue focusing public and DHHS attention on this significant social problem.

When this program is considered for reauthorization in 1981, we urge the Congress to review carefully the placement of OAPP within DHHS. Even if MCHA has not been created, we suggest that the Office be placed in a more appropriate location. We also urge the Congress to review the implementation of the legislation establishing this program; it is our impression that in the interest of providing services to young women already pregnant, too little attention has been given to pregnancy prevention.

We also note that, even though we urge that Title X family planning services be included in MCHA, we share the long-standing concern of advocates of the Title X program that it not be absorbed legislatively into related programs such as Title V, which also supports family planning. As we discuss in chapter 7, the Panel strongly endorses the continuation of categorical funding for family planning as embodied in Title X and does not see the proposed MCHA as changing the nature of Title X itself. We believe, however, that MCHA will provide an environment that will promote more cohesion between the various family planning programs.

Beyond these few comments, the Panel has chosen not to recommend how MCHA should be structured internally. However, as discussed in volume II of this report, we do recommend that the Title V program be established in legislation as a Bureau, which we refer to as the Bureau of Maternal and Child Health Services (BMCHS) (*1*).

Programs recommended for assignment to MCHA do not include every possible maternal and child health program or piece of program—notably those listed above under duty number 2 for MCHA. This is because the Panel believes that it is a false goal to try to place in a single agency all the programs that bear on the health needs of this population. Instead, the aim should be to assemble a critical mass of people and dollars capable of serving as the lead agency for maternal and child health within DHHS and providing much of the program coordination that is currently lacking. In our view, the primary value of MCHA is not that it would be the sole repository of all maternal and child health programs, but rather that it would be an organizational entity high enough in the bureaucracy and of sufficient stature and prestige to coordinate various programs and sources of funds in many separate agencies and to provide leadership in achieving the goal of ensuring that health services are provided in a coordinated fashion. Increased coordination among publicly financed programs is, in the Panel's view, as important as increasing the scope or appropriations of any single program. This is true most of all at the local level, where program coordination is crucial not only among public programs, but also between public and private efforts.

Nonetheless, we also urge that the Secretary of DHHS, the Assistant Secretary for Health, and the Administrator of the new Maternal and

Child Health Administration, and other departmental leaders periodically review the wisdom of adding other maternal and child health-related programs to those listed here. Programs within DHHS which the Panel saw no need to move at present but which could logically become a part of MCHA at some future time include, for example, the lead poisoning prevention and immunization activities of CDC and the Developmental Disabilities program of the Office of Human Development Services (OHDS).

A principal function of MCHA should be to encourage a variety of other DHHS programs to pay increased attention to issues of maternal and child health. For example:

- Institutes within the National Institutes of Health, beyond the National Institute of Child Health and Human Development, should be encouraged to sustain and increase their attention to maternal and child health problems that fall within their research mandates.
- ADAMHA should be urged to increase the extent to which its various activities relate to children, including the effects of adult alcohol, drug abuse, and mental health problems on children.
- The Health Resources Administration should be urged to focus its various health planning activities more strongly on the health needs of mothers and children.
- The National Center for Health Services Research and the National Center for Health Care Technology should be urged to devote a higher proportion of their research and evaluation activities to maternal and child health.

Many more examples could be cited. The important point is that although none of these programs should be included in MCHA because they are embedded in larger programs dominated by different social objectives or functions, all can nonetheless make important, often irreplaceable, contributions to maternal and child health. What is needed is greater emphasis within these programs on this population, and better coordination with other relevant programs. This is especially true of such DHHS programs as the community health centers, the National Health Service Corps, and the rural and urban health initiatives. Some of these programs are not providing health services to mothers and children, and must be encouraged to do so; and even those that do could do substantially more (*2*). The Panel believes that an agency such as MCHA is needed to help ensure that these various programs pay adequate attention to the health needs of mothers and children. Such leverage would be exerted through a variety of mechanisms including the review and comment function noted earlier, interagency agreements, our proposed Commission, and, of course, the leadership exerted by the MCHA administrator, colleagues, and outside advocates.

There are a few limitations associated with this proposal that the Panel considered specifically. The first is that by removing the Office of Maternal and Child Health and the Office of Family Planning from the Bureau of Community Health Services (BCHS), services for mothers and children are being separated from the Federal grant programs supporting community health centers, rural and urban health initiatives, and migrant

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health services in particular. Furthermore, withdrawing these programs from BCHS flies directly in the face of policies promoting family centered, comprehensive care. The Panel agrees that the new MCHA will need to make special efforts to retain the present close ties among these programs. However, the Panel also believes that the health needs of mothers and children will best be served in the long run by lodging programs directed toward this population in one agency with a clear maternal and child health focus. Experience has repeatedly shown that it is all too easy—and politically safe—to give inadequate attention to the needs of mothers and children, especially those who are poor, when they are forced to compete with other groups for attention and resources, as evidenced by the number of community health centers and other grant programs presently not providing comprehensive maternal and child health services (*2*).

A second issue considered by the Panel is that the head of an administration or agency is a political appointee, whereas the head of a bureau or office tends to be a career appointment. This raises the specter of MCHA becoming more vulnerable to electoral and congressional pressures, and therefore more political in discharging its duties. The Panel's view is that such political visibility is as much a potential advantage as a disadvantage. The presence of a political appointee at the head of MCHA may well work in favor of the health needs of mothers and children. At a minimum, for example, the attention of the DHHS Secretary is captured by the task of naming an administrator. More significant, an agency administrator has more opportunities for access to the Secretary and key department leaders than does an individual holding a lesser office. Further, a skilled political appointee may be especially effective in the important advocacy function.

A third possible limitation is that the proposed MCHA would be the only agency of PHS with a population rather than a functional orientation. In the Panel's view, the importance of the groups to be served by this new agency and the significance of their special needs more than justify whatever apparent inconsistencies would result from creating this agency.

Consideration was given to whether bureau status for the proposed collection of programs and duties would be preferable to creating a new agency. Although a bureau would definitely provide a clearer focus for maternal and child health within the department than currently exists, the Panel believes an agency would be better able to perform the proposed duties, particularly those associated with providing departmental leadership for maternal and child health and interdepartmental coordination. An agency rather than a bureau would also highlight the new national priority that the Panel argues should be accorded maternal and child health and the commitment to ensuring the availability of the set of basic, essential services. Certainly if a national health financing plan is to begin with universal coverage for mothers and children as the Panel advocates (see chapter 9), an organizational entity with at least the visibility of an agency rather than a bureau is warranted. Such an agency, in concert with HCFA, would be the logical set of offices and programs within DHHS to administer NHI. Thus the Panel believes that the MCHA is consistent with both its immediate goals of increased program coordination and prominence, and its long-term goals of national health insurance beginning with mothers and children.

THE RELATIONSHIP BETWEEN PHS AND HCFA

An obvious candidate for possible inclusion in MCHA is the EPSDT program of HCFA which, as part of the Medicaid program, is administered by the States. The Panel reviewed this option carefully and concluded that although moving EPSDT to MCHA has a certain initial appeal because it is a major source of child health funds, this would not be a wise move in the long run for two reasons.

First, removing EPSDT from Medicaid where it is legislatively based, would create not only significant management problems, but also the likelihood of increased operating problems at the State level, and the high probability of resulting major delays and disruption in providing EPSDT services to children.

The second and more significant reason is that the Panel believes the relationship of MCHA to EPSDT is only a small part of a much larger issue—the relationship of the entire Public Health Service to the Health Care Financing Administration. The outlines of this problematic relationship were summarized well for the Panel in a paper it commissioned:

> The Medicaid program was begun and continues as an offshoot of the welfare program. It was not conceived primarily as a health program but as an income maintenance program to help the eligible poor to pay for the high costs of medical care. This reasoning was reflected in the location of Medicaid until 1977 in the welfare administration unit of DHEW [the Department of Health, Education, and Welfare]. Medicaid shares with welfare the responsibility for establishing and terminating eligibility, for rooting out fraud and abuse, and for administration through a set of reluctant partners, the States, many of which seek to minimize the number of eligibles and the scope of the program. The mechanisms of reimbursement have received much attention, and the effects of rapid rises in health care costs have focused attention on cost containment rather than health needs.
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> Two important developments have taken place recently. The first was the development of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, which attempted to use the Medicaid program in a more aggressive fashion to identify children in need of health services and to meet those needs. That this program has had a difficult history should not be surprising given the basic characteristics of the Medicaid program. The CHAP [Child Health Assurance Program] proposal would carry Medicaid much further toward becoming a program for improving the health of its beneficiaries and not just an income scheme for paying expenses already incurred.
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> The second event was the transfer of Medicaid into a new agency in early 1977, the Health Care Financing Administration (HCFA). HCFA is attempting to provide a common administrative and policy

framework for Medicaid and Medicare, a difficult task given the very different characteristics of the two programs. This intent is illustrated in the HCFA organization, which does not have a separate organizational unit for Medicaid. It is reasonable to speculate that HCFA probably would administer any likely expansion of the Federal health financing role.

HCFA is often described as a health program, yet its major components have an income protection orientation and administer payment processes based on the current nature of the health care system. These programs, by emphasizing payment for services already obtained and by following many of the patterns of private health insurance, have reinforced the characteristics of the existing health system with its emphasis on hospitalization, specialized services, episodic care, and its disincentives for primary care, preventive services, and continuity of care. The addition of the PSRO's [Professional Standards Review Organizations] and other "quality assessment" programs to review the appropriateness of and necessity for care cannot overcome many of the basic incentive patterns created by the systems of reimbursement.

EPSDT and CHAP seek to change those patterns for some aspects of child health services. However, many other programs, mostly in the Public Health Service [PHS] , have been attempting to expand the capacity for primary care of poor populations in underserved areas. Other PHS programs have created and supported innovative patterns of care including health maintenance organizations (HMO's), midlevel practitioners, prevention and health promotion programs. Still other PHS programs support systems of information gathering and data generation, health planning, and resource development.

Since the creation of Medicaid, there has been difficulty in the coordination of its policy and operations with those of PHS. Examples of effective coordination can be cited in specific cases, but much evidence indicates separate paths and philosophies as well as the usual degree of territoriality.

The actual and potential relationships among the program elements of HCFA and PHS justify the need for a much closer relationship. Close cooperation will be required because of the prospect of CHAP and further developments in health financing programs that require inputs from health services oriented staff (e.g., the end-stage renal disease program), the growing need to improve and monitor the effectiveness of health services (through research, service innovations, assessments of efficacy, health planning, and health statistics), and the need to build local capacities for services (especially primary care for the poor and rural areas). The case for a closer relationship is especially strong in the area of maternal and child health, because of (1) EPSDT and CHAP; (2) the strong emphasis in PHS on primary care including disease prevention and health promotion, which are especially large components of maternal and child health services; (3) the need to work with other programs and public delivery systems, such as schools and public health departments which do not have the fee-for-service reimbursement orientation of HCFA; and (4) the need to couple the professional knowledge, innovative capacities, and the commitment to improved health of the PHS with the leverage of the large dollar flow through Medicaid (*3*).

The Panel shares this assessment of the PHS–HCFA relationship and therefore viewed the idea of moving EPSDT to MCHA as a piecemeal approach to a difficult problem. Instead, we considered a variety of ways to link the service orientation of PHS with the financing and management capacity of HCFA for the benefit of mothers and children in the immediate future and for the full population over the longer term. Given the possibility that any extension of the Federal health financing role to increase health services for mothers and children would rely heavily on HCFA, the Panel believes it is a matter of some urgency that HCFA and PHS be brought into a closer relationship. The creation of MCHA and other actions outlined later in this chapter are steps in that direction, but are not sufficient to solve the problem. And radical suggestions such as transferring all of the community oriented activities of the PHS to HCFA are easily dismissed.

What seems to be needed is some mechanism to reorient HCFA policies and procedures (especially Medicaid reimbursement policies) to a greater emphasis on the goals of health promotion and the provision of high quality and appropriate health services, along with efficient management of the bill-paying mechanism and cost containment. Current Medicaid legislation, for example, does not require the reimbursement of many of the health services which the Panel has found central to protecting and promoting maternal and child health, such as immunizations, nutrition services, prevention oriented counseling, prenatal care provided in local public health departments and some hospitals, and many mental health services. Consequently, many States have chosen not to reimburse such services. Moreover, because Medicaid reimbursement policies are tied to welfare eligibility and because an individual's or family's eligibility for welfare may change often, the goal of providing continuous care is often circumvented.

One way to encourage needed changes in HCFA is the Panel's proposal that the Congress establish a Board on Health Services Standards. As discussed in chapters 5 and 9, this body would advise third-party payers and other groups on the health services needed by mothers and children, on the circumstances under which many services are best provided and financed, and on the relationship of payment practices generally to the structure and functioning of the health system. A major audience for such guidance is, of course, HCFA. We have proposed that the Board's powers be advisory. We also recommend, however, that the Board be set up in such a way that pressures are created to encourage HCFA and other public third-party payers in particular to attend carefully to the Board's views. For example, we suggest that if HCFA chooses not to follow the Board's advice regarding a particular service or set of services, HCFA be required to report to the Secretary of DHHS and to Congress in a highly visible way why it is rejecting the guidance. That is, the burden should be on HCFA to say why not, rather than on the Board to say why. If, for example, the Board reviews carefully the issue of home visiting—the content of such visits, that levels of professionals that should conduct home visits, the various ways such visits should relate to existing provider arrangements, their costs and benefits—and recommends that third-party payers finance home visiting under certain specific conditions, the burden would be on HCFA to follow such guidelines to the extent permitted by Medicaid law or, if it wishes to reject them, to defend its policies publicly.

The Panel also believes that some structural changes within DHHS will be needed in the long run to focus HCFA's role on running the eligibility and payment mechanisms with policy determination regarding health issues heavily influenced by individuals and structures where health concerns are paramount. Two possible strategies toward this end are to bring HCFA under the leadership of the Assistant Secretary for Health, or to make both PHS and HCFA responsible to an Undersecretary for Health. The Panel does not feel it appropriate to press a specific approach to this problem. However, *we strongly recommend that the Secretary of DHHS give serious and prompt consideration to the possibility of restructuring the HCFA–PHS relationship in order to ensure that the orientation of HCFA emphasizes health promotion and high quality health services along with efficent management and cost containment.* In so recommending, we are aware that within the last couple of years, HCFA and PHS have worked hard to develop closer ties and more compatible policies particularly in the child health area. We are supportive of the progress that has been made, but find that the fundamental structure and orientation of the two components remain disparate. If the PHS/HCFA relationship is left to continue as is, the Panel is deeply concerned that a national focus on disease prevention, health promotion, and primary care—for all citizens, not just mothers and children—will remain elusive.

A NATIONAL COMMISSION ON MATERNAL AND CHILD HEALTH

A second major initiative proposed by the Panel to complement the establishment of MCHA is *the creation in legislation of a National Commission on Maternal and Child Health to perform the following duties:*

- Recommend policy changes in Federal maternal and child health programs to improve their effectiveness and to enhance coordination among programs.
- Report every 3 years (with brief annual updates) to Congress, the DHHS Secretary, the Assistant Secretary for Health, and the HCFA Administrator on the health status and unmet service needs of mothers and children, including attention to important trends, emerging needs, and possible preventive strategies.
- Report periodically to Congress, the DHHS Secretary, the Assistant Secretary for Health, the HCFA Administrator, and other Federal agency directors, as appropriate, on Federal research and training activities affecting the quality and availabili-

ty of maternal and child health services, and on regulatory activities related to reducing environmental risks to the health of mothers and children.

- Conduct studies and issue reports to the public on health issues pertinent to children and pregnant women, as desired by the Commission.
- Serve as an advocate, particularly in Congress, for the health needs of mothers and children.

Further, to ensure that the new Title V requirements outlined by the Panel in Volume II are implemented with adequate advice and guidance, the legislation establishing the Commission should direct it to set up a subcommittee with special responsibilities relating to the Title V program. This subcommittee should be responsible for reviewing and approving the annual Federal plan for support of research, training, and demonstration projects under Title V, and making recommendations to the Director of BMCHS on policy matters relating to the general administration of the Title V program.

These duties are interrelated and mutually reinforcing. For example, the Panel believes that the broad understanding of maternal and child health that the Commission will necessarily develop in producing its report every 3 years will make the annual review and approval of selected Federal Title V plans a more meaningful and useful exercise.

The Panel recommends that the Commission be composed of citizen members appointed by the Secretary of DHHS for terms not to exceed 3 years and in a manner that allows for approximately one-third of the membership to rotate annually. The Commission should be chaired by one of its members, designated by the Secretary. The Commissioners should be drawn from a wide range of fields pertinent to maternal and child health, including but not limited to practitioners, administrators and planners, advocates and parents, researchers, and individuals from such areas as health education and social services that are intertwined with so many maternal and child health programs. No single profession or perspective should dominate, and the group's composition should reflect the numerous aspects of maternal and child health covered by this report. The Panel would suggest four particular categories of membership for inclusion in the Commission. First, the *Panel recommends that the Commission include at least one present or former member of a State Maternal and Child Health Council* (see chapter 10) to help ensure that the group is aware of the great range of progress, opportunities, and problems that exist at the State and local level. Second, to increase the likelihood of a productive relationship between the Commission and the Congress, the *Panel recommends that the chairman of each of four committees of Congress be asked to suggest to the Secretary of DHHS the names of two or three individuals to serve on the Commission. Third, the Panel recommends that the secretaries of the Departments of Agriculture, Transportation, Housing and Urban Development, Education, and Defense be invited to name formal observers to the Commission.* Additional representatives from other departments and agencies, or from any State or local program or outside group should, of course, be invited to join the Commission discussions when appropriate. And finally, the

Panel recommends that an ex officio slot on the Commission be established for the individual or office head designated by the DHHS Secretary as the Secretary's principal agent for ensuring interdepartmental coordination for maternal and child health. (See next section.) Similarly, the Administrators of MCHA, HCFA, and the Office of Human Development Services (OHDS) should be actively involved in the deliberations of the Commission.

The Secretary should place the Commission within MCHA and ensure that it is provided with adequate staff and financial support. Staff should be selected by the Commission chairman to help provide independence.

The Panel recognizes that Washington abounds with commissions and advisory groups, and that even those that begin their life with a clear sense of mission and commitment may over time become unimaginative bodies dulled by routine. The Panel believes that although the duties and membership of the Commission it has outlined lessen the prospect of such decline, it may be prudent to set the Commission up for a finite period of perhaps 6 years only (thereby allowing two full cycles of members). At that point, Congress and the DHHS Secretary could assess the merits of continuing the life of the Commission.

A COORDINATING FUNCTION AT THE LEVEL OF THE SECRETARY

The Panel recognizes that the authority of the Secretary of DHHS is one of the most powerful tools available to push for the kind of program coordination needed for MCH services. As head of the department, the Secretary and his or her agents can be uniquely effective in encouraging even the most reluctant agencies to work together. The Panel would therefore urge that the Secretary designate a person to serve as the principal agent of the Secretary in ensuring that the health needs of mothers and children are addressed effectively and efficiently by the many components of DHHS. Toward this broad objective, and in cooperation with PHS, HCFA, and OHDS especially, this individual should undertake such tasks as:

- Encouraging formal interagency agreements on specific issues
- Convening of interagency task forces under the auspices of the Office of the Secretary to work on specific problems
- Helping to ensure that the formal review and comment function assigned to MCHA occurs routinely
- Serving as an ex officio member of the National Commission on Maternal and Child Health
- Assisting MCHA develop its position as the lead agency for maternal and child health by including it in appropriate decisions and discussions at the Secretary's level, and facilitating discussions between MCHA and other agencies and departments as needed

It is the Panel's view that such assistance and leadership from the Office of the Secretary would complement MCHA and the Commission, and that in the aggregate all three components hold the promise of meaningful, tangible progress within DHHS to benefit mothers and children.

JOINT HEARINGS

The Panel believes that the Congress also has a special role to play in helping to coordinate maternal and child health programs both inter- and intradepartmentally. It is widely recognized that one of the reasons programs may not complement one another adequately—even those administered within the same department—is that each may be under the jurisdiction of a different Congressional committee, which in turn typically implies different program orientations, constituencies, priorities, and so forth. For example, two of the most important programs for mothers and children within DHHS, Title X and Medicaid, are under the jurisdiction of two different committees of the Senate—Labor and Human Resources, and Finance, respectively. Furthermore, we find that the fragmentation caused by such different jurisdictions is compounded when programs are also administered in different departments. For example, the WIC program and the PHS programs are not only under the jurisdiction of separate committees, but also administered in different departments.

Although a long-term goal for bringing such programs into closer alignment might be a reorganizing of congressional jurisdictions with regard to maternal and child health programs, we find such a suggestion politically untenable at present. As a more feasible and practical goal, we instead *recommend that within both the House and the Senate, joint oversight hearings be convened periodically by the committees having responsibility for different maternal and child health related programs in order to assess the adequacy of the various programs' coordination and complementarity. We place particular emphasis on hearings regarding the coordination among maternal and child health programs administered by different departments.* For example, to assess the relationship between the WIC program within USDA and the various health service activities of the Public Health Service, joint oversight hearings should be held on the Senate side by the Agriculture Committee and the Committee on Labor and Human Resources; on the House side, the appropriate committees are the Committee on Education and Labor and the House Interstate and Foreign Commerce Committee.

Other possible topics for joint hearings include:

- The extent to which community mental health centers supported by DHHS (NIMH specifically) meet the mental health needs of handicapped children served through the P.L. 94–142 program of the Department of Education
- The relationship between DHHS efforts and those of the Department of Housing and Urban Development to minimize risks of lead-based paint poisoning to children specifically and more generally to promote safe housing
- The relationship between automobile accident prevention programs within the Department of Transportation and parallel interests within DHHS

THE ROLE OF THE REGIONAL OFFICES

As an arm of the Federal Government, the regional offices of DHHS have a unique potential for easing many of the problems of program coordination described above. However, the Panel did not give extensive attention to the role and functions of the regional offices, primarily because many of the concerns that have been raised over the years about the performance of the regional offices are not specific to maternal and child health but instead center on a more general problem—namely, that the authority of the regional offices has long been unclear because they are caught between Washington and the States. Regional staff are often forced to cope with program inconsistencies, rigidities, poorly conceived objectives, and changing directives from headquarters. They are subjected to criticism from both sides as they are called upon to correct the ambiguities and imperfections of Federal programs. Although the Panel offers no comprehensive plan to improve the regional offices, part of the success of our proposal to expand and strengthen the Title V program and to increase the availability of a set of minimum, basic services will depend on the ability of the regional offices to provide expert advice, consultation, and guidance to the States in discharging their increased responsibilities. Moreover, the regional offices will need to assist the Federal Government in monitoring the adequacy of State performance in many diverse areas, including statewide planning, quality assurance of maternal and child health services, and compliance with whatever service standards MCHA establishes with regard to the minimum, basic services especially. To increase the capability of the regional offices to discharge their responsibilities under the proposed mandate of MCHA, as well as to improve their relationship to existing programs, the Panel recommmends that:

(1) The regional maternal and child health staff should be adequate in number, training, and experience to carry out assigned responsibilities, particularly in helping the States assume a stronger role in improving maternal and child health. The regional office staff should include qualified individuals (preferably with State or local experience) in such fields as medicine, nursing, social work, nutrition, dentistry, and epidemiology-statistics. The regional offices should also retain adequate staff skilled in the fields of planning, management, and related administrative functions to assist the States.

(2) Expertise in other disciplines such as speech and hearing, physical or occupational therapy and health education should be available either from the central office or staff assigned to cover two or more regions.

(3) Regional staff should be permitted to work full-time with their assigned States to improve and extend health services for mothers and children. To do so, staff should be both advocates of the States to the Federal Government (through such activities as representing the State perspective in various Federal forums; making States aware of available grant funds, and helping them to obtain them; advising States regarding allowable flexibility in interpreting regulations in order to expand and enhance services;

and interpreting Federal guidelines and policies to the States) and "prodders" of the States (by such activities as program development, providing program models from other areas, and developing improved capacities for evaluation, planning, staff training, and constituency building).

(4) Regional staff should not only give attention to programs within MCHA, but also to other DHHS-funded programs which have maternal and child health service components such as Medicaid; the major grant programs of HSA, such as the Community Health Centers; the grant programs of HCFA; and programs such as WIC and P.L. 94–142, which are funded by departments other than DHHS but bear directly on maternal and child health.

Achieving this maternal and child health focus in the regional offices might be facilitated by there being a designated maternal and child health representative in these offices.

REFERENCES AND NOTES

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SECTION V

MANPOWER AND RESEARCH

CHAPTER 12

HEALTH PROFESSIONALS

Because several other groups have completed or are developing major reports on manpower issues relevant to maternal and child health policy, the Panel chose not to perform a comprehensive manpower analysis of our own (*1, 2*). Nonetheless, we recognize that the views and recommendations presented in other sections of this report contain major policy implications regarding the training and deployment of professionals in maternal and child health. As we see it, these include:

- The changing profile of primary care for mothers and children, with its emphasis on health promotion and disease prevention activities, requires new components in the training of all primary care providers.
- Meeting the health needs of pregnant women, children, and adolescents in an adequate fashion will increasingly require a team approach to the delivery of primary care, and exposure to team modes of practice must therefore become an integral part of the training of primary health care professionals.
- The anticipated increase in the overall supply of primary health care providers in the coming decade makes possible, but does not by itself assure, better access to health care for those most in need. Improved distribution of services will depend, among other things, on alterations in the deployment of National Health Service Corps personnel and on creative use of providers with differing levels of training and expertise.
- Training of maternal and child health personnel involved in program administration and policymaking at the Federal, State or local level must be modified to equip such professionals with the broad range of skills required for management roles in complex, interrelated service systems (public health, private medical practice, social services, education, etc.).

In the discussion that follows, we have focused primarily on the "frontline" providers of health care for mothers and children—physicians, nurses, midlevel practitioners, and dentists. In so doing, we in no way wish to suggest that these are the only professionals who are significant for maternal and child health. Indeed, as we have repeatedly stressed throughout this report, adequate health care for mothers and children now requires the skills and expertise of many other professionals in addition to traditional medical personnel. Teachers, nutritionists, psychologists, social workers—these are but a few of the groups with significant contributions to make in maternal and child health care. We limit our focus in this chapter only because of the restrictions on our time and staff resources and because other bodies are in the process of addressing manpower issues in greater depth.

THE CHANGING PROFILE OF CARE: TRAINING IMPLICATIONS

As discussed earlier in this report, the profile of maternal and child health needs has changed significantly over the course of the last few decades, a development that requires a concommitant change in the training of primary care providers and the way in which they practice. *The growing importance of psychosocial factors in health care, and our increasing emphasis on health promotion and disease prevention activities in the delivery of health services, must be reflected in the training of health care providers, especially those providing primary care services.* This means that:

- Training programs for such health professionals must be enlarged in scope so that these individuals not only acquire skill in coping with disease processes but also gain a firm foundation in human growth and development, and understanding of the influences of genetic, familial, environmental, and social factors on the health status of children and mothers.
- The importance of nutrition, counseling, prevention of disease, and education for health-promoting behavior should become firmly established components of training and practice, and should be reflected in requirements for entry into the health professions and for continuing education.

There are encouraging signs that the health professions are moving in the right direction. The training and practice of nurses engaged in maternal and child health care have long emphasized precisely those concerns the Panel sees as central. The American Nurses' Association is currently offering certification examinations in the primary care specialties which serve as a credentialing mechanism analogous to the medical boards for physicians. The National Association of Pediatric Nurse Practitioners and Nurse Associates also offers certifying examinations, and it is worth noting that the training of these midlevel practitioners offers an excellent integration of medical skills with psychosocial and public health aspects of care.

At the physician level, the recent report of the Task Force on Pediatric Education stressed that medical education for primary care physicians should emphasize human growth and development and the biosocial aspects of pediatrics and adolescent medicine (*2*), a recommendation with which the Panel concurs. In fact, a similar emphasis is needed in the training of all primary care physicians who see substantial numbers of pregnant women, mothers, and children. This includes obstetricians-gynecologists, general practitioners, family practitioners, and internists.

The Panel is aware of the magnitude of the difficulty in effecting change within professional education programs. One of the major problems is that medical education remains for the greater part oriented to acute illness and hospital care. In the hospital setting, care of the more serious diseases of mothers and children is taught, and it has been very easy to assume that disorders not requiring hospitalization are simple and can be handled using the same knowledge gained by caring for hospital patients. As a result, physicians learn a great deal about diseases they may never see again or will refer to specialists after initial case recognition.

Similarly, in most teaching centers, inpatient care responsibilities are heavy and must be met even as changes are being made to provide more training experience in ambulatory care. This is far from easy, since teaching hospitals typically depend upon physicians in training to provide direct inpatient services. Further, a number of community settings that would make excellent training sites—such as mental health centers, public health clinics, school health units, comprehensive care centers, and the like—lack the financial resources to support either trainee or teacher. Indeed, medical schools have a difficult time financing ambulatory care training experiences in general because outpatient services are so poorly reimbursed compared with inpatient care.

In recognition of the need for a shift in the emphasis of pediatric training and research, the Robert Wood Johnson Foundation and W.T. Grant Foundation are supporting academic development programs in general pediatrics at a limited number of medical schools (*3*). The Health Resources Administration also has had a grant program in operation for a number of years to fund general pediatrics and internal medicine training programs. Such programs are intended to improve teaching and research in emerging areas of general pediatrics and to encourage development of innovative approaches to financing, as discussed in chapter 9. If they prove successful, their major elements could be generalized to other child health care training programs.

Team Practice in Primary Care

It is obviously unrealistic to expect that physicians, nurses, and midlevel practitioners master in depth all the fields of knowledge that bear upon the physical and mental health of children and pregnant women. It is also unwise, in our view, to encourage practice patterns that isolate primary care physicians from other personnel whose expertise complements their own. *Therefore, the Panel believes that many of the complex health needs of pregnant women and children are especially well met through the use of team approaches to care involving substantial collaboration among various types of health professionals and strong links to health-related support services. Teamwork in delivering health services to this population* *can have various forms, each suited to different situations. To encourage team modes of practice:*

- The team concept should be firmly established in training, and supported in practice by organizational and financing arrangements.
- Joint training experiences should be designed for various groups of health professionals to encourage increased understanding and respect among the various professions for the unique contributions different disciplines can make to maternal and child health care.

The concept of a team approach to primary care does not dictate adoption of any one organizational arrangement. Team care can be provided in an organized setting such as a comprehensive care center, which brings together a number of professionals from different disciplines, or by a solo practitioner and nurse utilizing referral and consultation linkages with a wide range of other service providers. What is important is that the concept of team care be firmly instilled in health professionals during their training, and that organizational and financing arrangements support such an approach in practice.

The Panel noted that there is already a trend among pediatricians away from solo practice and toward work in groups. A 1978 survey by the American Academy of Pediatrics (AAP) showed more than half (56 percent) of practicing pediatricians were in group practice, compared with 30 percent in solo practice (*4*). While this trend may stem largely from a desire to share overhead expenses and coverage responsibilities, group practice does encourage consultation and cooperation among health professionals. Further, it appears that the trend toward group practice is likely to continue and that it will increasingly include employment of midlevel professionals such as pediatric nurse practitioners. When asked to identify the "ideal" practice pattern for the future, a plurality of pediatricians now in practice (43 percent) and a majority of those now in academic medicine (55 percent) selected a group of pediatricians, all with areas of special interest, working in cooperation with pediatric nurse practitioners. This model, the AAP survey noted, was chosen even though less than 5 percent of those now in practice currently follow it (*4*). The Panel endorses both this model of group practice and the close cooperation of practicing pediatricians with colleagues in teaching centers. We believe such patterns improve the quality of care and should be encouraged for other primary care physicians as well.

Unfortunately, primary care physicians, nurses, midlevel practitioners, and others typically do not receive major combined training experience, a lack that unquestionably affects their willingness and ability to work with each other effectively in practice later on. For example, the AAP survey found a pronounced correlation between a pediatrician's experience working with a nurse practitioner and his or her endorsement of the value of such midlevel personnel. Familiarity, in this instance, breeds respect, the survey found. The Panel believes greater efforts must be made to ensure that exposure to team practice modes becomes an integral part of the training of all health professionals involved in the delivery of primary care to mothers and children.

SUPPLY AND DISTRIBUTION OF PRIMARY HEALTH CARE PROVIDERS

Because the child population is expected to increase relatively little over the next 10 years, while the supply of health care providers will grow significantly, the major manpower challenges in maternal and child health are not simply numerical in nature. Rather, the Nation must strive to produce the right mix of health care providers, ensure they are trained to cope with the real problems of mothers and children and see to it that they are distributed in a manner that assures access to appropriate health care for all our citizens.

Supply Projections

In recent years a number of individuals, agencies, and expert commissions have attempted to assess how many practitioners are required to meet maternal and child health care needs. Unfortunately, none of these manpower studies has included a thorough analysis of maternal and child health needs, even though such an analysis is essential for reaching logical decisions about the appropriate number and mix of child health care practitioners. The Panel views with considerable skepticism the assertion by some that there will be "too many" child health care providers by 1990 or 2000, given the variables involved in supply projections and the extent of unmet health care needs. It is unquestionably true that the supply of primary care physicians will increase substantially in coming decades, and also likely that the supply of midlevel practitioners such as certified nurse midwives and nurse practitioners will grow, but the effects of this manpower increase remain to be seen.

What are the projections? After years of decline, the supply of primary care physicians is now increasing, and doing so at a pace that outstrips population growth. In 1978, for example, there was one general pediatrician per 9,200 persons. By 1990, there will be one per 6,500 population (*1*). Similar trends are evident for general and family practitioners, internists, and obstetrician-gynecologists, the other principal providers of primary care to mothers and children.

In overall numbers, the Graduate Medical Education National Advisory Committee (GMENAC) projects the following physician increases between 1978 and 1990: general pediatrics, from 23,800 to 37,750, up 59 percent; general family practice, from 54,350 to 64,400, up 18 percent; general internal medicine, from 48,950 to 73,800, up 51 percent; and obstetrics-gynecology, from 23,100 to 34,450, up 49 percent (*1*).

Although the 1980 GMENAC report concluded there will be an overall physician surplus of 70,000 by 1990 and of 145,000 by the year 2000, little of the projected excess will come in primary care. Indeed, the supply of primary care physicians will be very near to the estimated need if GMENAC projections are correct. This distinction may not always be made by policymakers, but it is an important one. *The Panel therefore recommends that any pressures to cut back support for the training of maternal and child health professionals be resisted.*

The Panel's recommendation in this regard applies not only to primary care physicians but also to nurse practitioners and similar midlevel professionals serving mothers and children. GMENAC estimates that the supply of such practitioners will double, from approximately 20,000 to 40,000, between 1978 and 1990.

There has been great interest in whether the use of midlevel practitioners can increase physician productivity, reduce overall costs of care, and improve quality and appropriateness of care. None of these questions has been easy to answer because the impact of a midlevel practitioner depends heavily upon how the individual is used by the institution or physician with whom he or she is associated. The practitioner may be used to speed the flow of patients, to provide services not previously offered, or to allow the physician to spend more time with patients requiring his or her special skills.

In general, use of nurse practitioners tends to increase access and quality of care, but may not significantly reduce health care costs in the short term. However, midlevel practitioners cost far less to train than physicians and receive lower incomes. The Congressional Budget Office has concluded that midlevel practitioners can improve the cost effectiveness of medical practice precisely for this reason (*5*).

The Panel believes midlevel practitioners have an important contribution to make in the team approach to maternal and child health care which we advocate strongly. Their skills in communication, in case management, in health promotion, and in preventive care offer major benefits to mothers and children. *We therefore urge that training and use of midlevel practitioners be supported and expanded.* Steps toward this end include continuing support of training programs for such personnel, encouragement of team training with physicians, incentives for public programs and private practitioners to hire these health professionals, and the development of organized practice settings which allow appropriate modes of team practice to flourish. In some States, changes in the law will be required to enable midlevel practitioners to participate fully in the delivery of primary care in organized practice settings.

The growth in numbers of midlevel practitioners, while significant, should not be allowed to obscure the fact that there are far more registered nurses (RN's) in practice than there are newer professionals. According to the American Nurses' Association, there are an estimated 1,027,307 nurses in practice in the United States in 1980, or approximately 472 nurses per 100,000 population (*6*). Although there are no numerical estimates available, a substantial proportion of these nurses are engaged in providing health care to pregnant women, mothers, and children of all ages—in hospitals, clinics, health departments, comprehensive care centers, schools, physicians' offices, and other settings. Indeed, nurses have traditionally played an extremely important role in maternal and child health. Experience has shown they are especially valuable in providing preventive care, health promotion and education, assessments, and counseling services. Because such services are central to the health care needs of mothers and children, and because nurses remain an important part of the primary care team, the Panel shares the concerns of other groups about the current and anticipated shortage in the numbers of RN's actively employed in nursing.

The availability of adequate dental manpower is also of concern. As in the case of physicians, the supply of dentists has been increasing rapidly in recent years and will continue to do so in the decade ahead. In 1979, there were approximately 123,500 active dentists in the United States, a total that is expected to grow to 156,290 by 1990 (*7*).

While average dentist-to-population ratios are increasing fairly rapidly, a number of population groups and geographic areas remain underserved. Thus, while there are 56 dentists per 100,000 population nationwide, the average drops to 26 per 100,000 in counties where the principal city has a population of less than 5,000 (*8*). Children in such areas, and low-income and minority children, continue to suffer from inadequate access to and use of dental services. There is also a major problem of inadequate access to dental auxiliaries for preventive services.

Improved Distribution

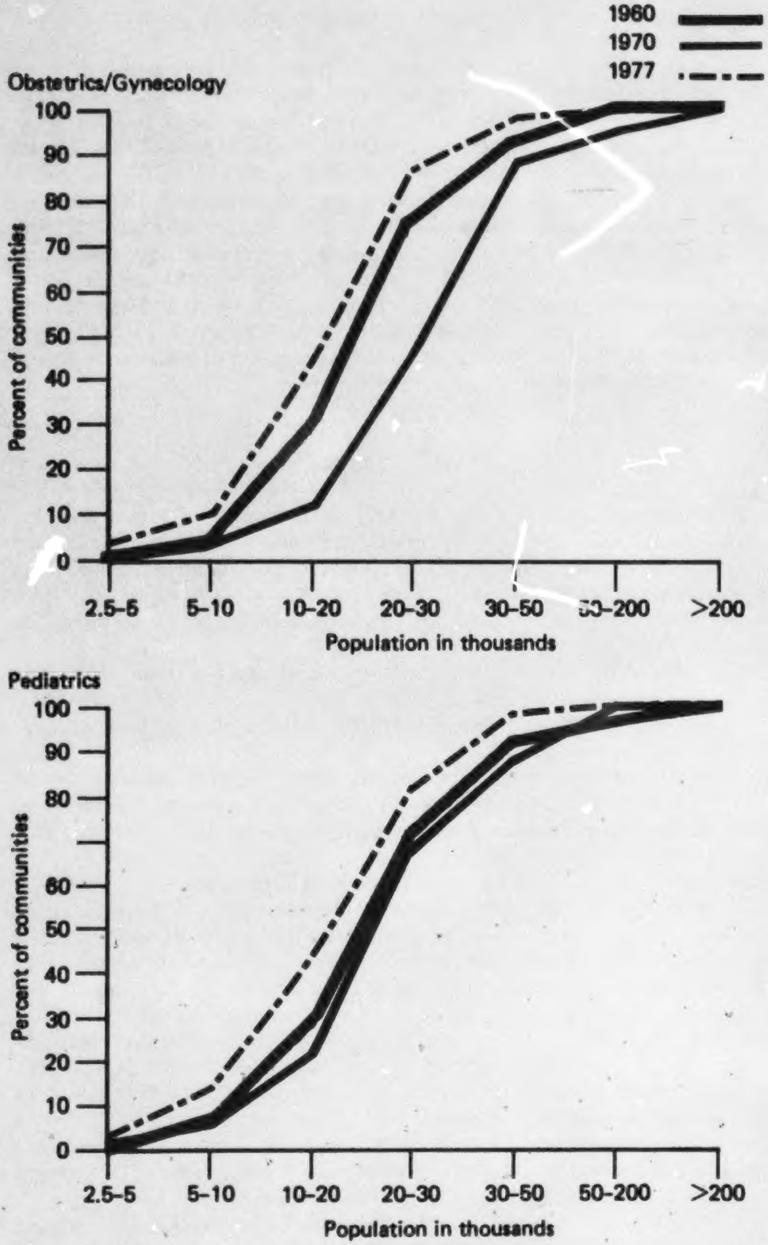
Despite the increases of recent years in the supply of primary health care professionals serving mothers and children, rural communities and central cities remain underserved, as do certain population groups such as low-income families and minorities. The Nation has employed three strategies to increase the availability and accessibility of primary care for these areas and groups:

- Training incentives to increase the number of new physicians entering family practice
- Deployment of National Health Service Corps personnel to underserved areas
- Use of nurse practitioners and other midlevel practitioners in underserved areas, with remote physician backup and supervision

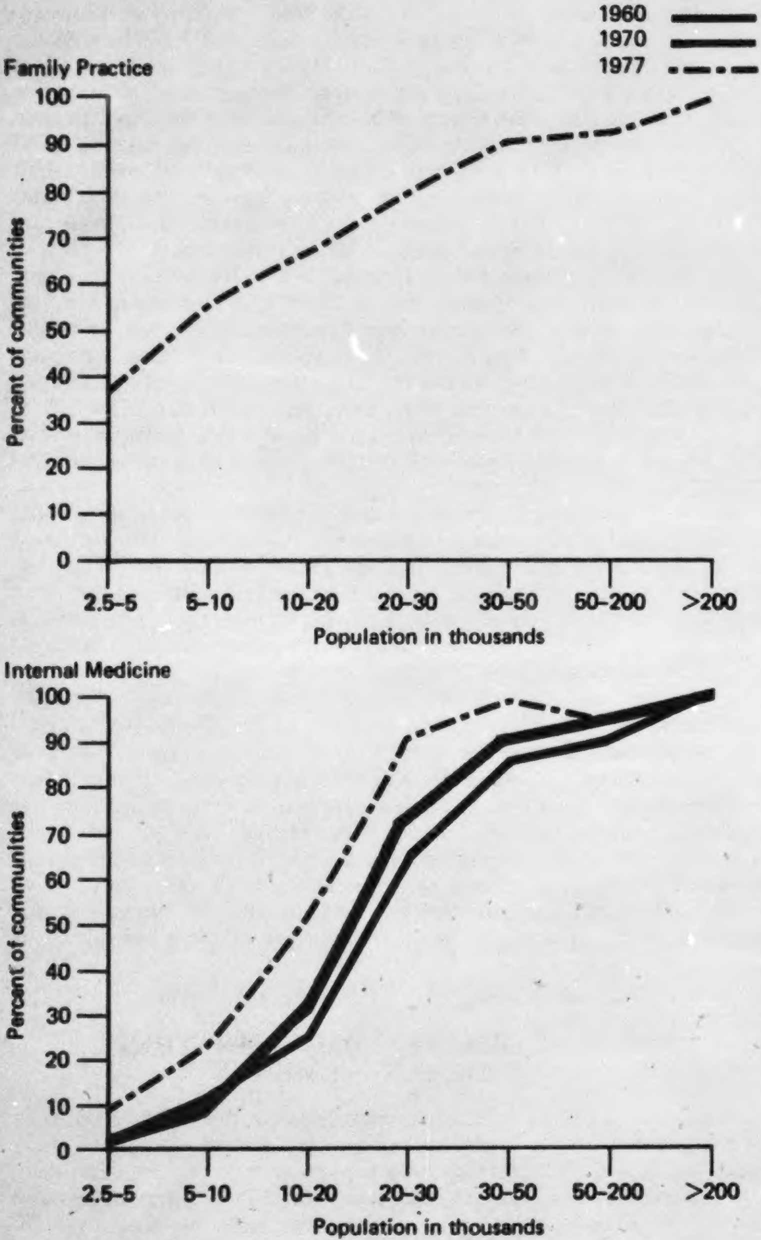
Each of these strategies has already met with some measure of success and each shows continuing promise.

The increase in the numbers of family practitioners, for example, is helping to bring primary care physicians to communities that are too small to support practices of even such broadly oriented specialists as pediatricians and obstetrician-gynecologists. More than half of all recent family practice graduates have settled in towns of less than 25,000 population. In fact, nearly one-third of recent family practice graduates have located in areas that are more than 25 miles away from a medium-sized city (9). This is in contrast to pediatricians, approximately 90 percent of whom are in urban and suburban areas, according to the 1978 survey of the American Academy of Pediatrics. Since, according to 1970 Census data, almost 20 percent of children live in rural areas, it is evident that family and general practitioners will remain a major source of primary care for children and their families in those areas (*10*).

The deployment of National Health Service Corps (NHSC) personnel to underserved rural and central city areas is also increasing. At present, a total of 2,060 physicians, dentists, nurse practitioners, physician's assis-



Percent of communities with board-certified specialists, according to community size: United States, 1960, 1970, and 1977



Percent of communities with board-certified specialists, according to community size: United States, 1960, 1970 and 1977 (Cont.)

tants, and other health personnel are in the field, a majority of whom are in comprehensive care settings. Included are Community Health Centers, Improved Pregnancy Outcome Projects (IPO's), and Improved Child Health Projects (ICHP's). Pregnant women, mothers, and children are major beneficiaries of the talents of NHSC personnel employed in such programs. However, the potential contribution to maternal and child health care by NHSC personnel assigned to State and local health departments is being limited by the existing requirement that States reimburse the Federal Government for all reasonable costs, including salary, associated with the placement of NHSC professionals.

The Panel recommends that the National Health Service Corps not only maintain but increase its complement of health care professionals serving mothers and children. We further urge that policy be changed to permit placement of these professionals in all kinds of comprehensive primary care centers in underserved areas, including those sponsored by local and state health departments, without requiring reimbursement to the federal government of costs associated with their deployment. Such placements should serve to expand services and not to replace existing care from local providers.

As the NHSC changes from a small volunteer program to a much expanded scholarship program with a service requirement, issues involved in site designation and placement of personnel become more complex. Support for Corps personnel is crucial, both during training and when in practice. The Panel considers it essential *that state or regional systems be developed to provide clinical and managerial support relevant to maternal and child health care.*

A third approach to improving the supply and accessibility of primary care providers in underserved areas involves the use of nurse practitioners and other midlevel professionals. Various studies suggest that such practitioners, with adequate physician backup, provide primary care services of high quality and improve access to care for many families, especially residents of communities with relatively few physicians. In comprehensive care settings, in schools, in day care centers, and elsewhere, nurse practitioners can provide valuable and cost-effective services. The Panel feels it is important that policymakers, physicians, and program managers continue to expand the use of these individuals in innovative ways.

PUBLIC HEALTH ADMINISTRATION AND MANAGEMENT

Those who join the public health professions in the 1980's, whether to deliver services directly or to plan and administer service programs at the local, State, and Federal levels, will face more complex organizational, fiscal, and political challenges than ever before. Program managers and other key administrators and policymakers must be able to work effectively within and across bureaucracies, with elected officials at all levels, and with members of the medical profession and a variety of interest groups.

To a large extent, the ability of maternal and child health programs to compete at all levels for scarce resources will depend upon the competence, commitment and training of a relatively small cadre of professionals whose careers are devoted to the improvement of service systems for mothers and children. Indeed, the success of the programs themselves may turn upon the quality of their administration and management. A recent study of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, for example, found it had the greatest impact in States with a core group of committed officials working energetically to advance the cause in the State legislature and in local communities (*11*). Such officials provided a resource base and an infrastructure which were critical to program success.

Maternal and child health program managers, policymakers, and administrators work in a variety of settings. Some demand medical training and entail heavy direct or indirect patient care responsibilities; others do not. Examples of some job opportunities in maternal and child health include Crippled Children's programs, centers for handicapped children, Improved Pregnancy Outcome projects, local and State government maternal and child health programs, faculty positions in university schools of public health or schools of medicine, newborn services or regional perinatal centers in hospitals, and college health or adolescent health service programs (*12*).

It is the Panel's impression that few if any university graduate programs do an adequate job of combining medical and public health training with each other, or with training in public policy skills. Yet it is precisely this mix of expertise that is often most needed by maternal and child health program managers and administrators. *The Panel recommends that training in selected public health disciplines be combined with training in public policy and public administration to equip students with the broad range of skills required for successful management of complex and interrelated service systems—public health, social services, education, and others.*

The content of the training received by maternal and child health professionals also needs to be updated to reflect the significance of such factors as changes in the American family structure, the impact of environmental and behavioral factors on health, new techniques for reducing infant mortality and morbidity and the incidence of low birth weight, the special needs of minority groups, cultural aspects of health care provision, and the changing structure of primary care delivery systems. *In addition, efforts need to be made to encourage closer collaboration between the public health and private care sectors, and between preventive and therapeutic health services.* We must bridge the chasm separating maternal and child health as a public health responsibility from pediatrics and obstetrics as private, medically oriented professions.

Finally, the Panel believes that university faculty involved in training public health professionals need to know more about programs currently in operation or planned so they can prepare students for career opportunities and service requirements that actually exist, or are likely to in the near future. Equally important, public health policymakers and program managers need to know what manpower is available, and with what expertise, to staff existing and proposed programs. Thus closer communication and collaboration are needed between the educators who are training public health professionals and the program planners and administrators who will ultimately employ them.

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CHAPTER 13

RESEARCH AND DATA NEEDS

Other chapters of this report contain numerous suggestions for needed research. Some call attention to specific topics in need of exploration; others simply urge continued research in a broad area. Both the constancy and the repetition of this research theme reflect a strong consensus within the Panel that the search for new knowledge and its use to ease burdensome problems are among the most promising and effective means the Nation can employ in its efforts to protect and advance the health of mothers and children.

The Panel's commitment to research is as strong as its advocacy of improvements in the organization and financing of services, in the physical and social environment, and in the management structures that administer health services for mothers and children. These strategies are complementary and mutually reinforcing; a wise and balanced approach to promoting the health of mothers and children must include new commitments and directions in all of these areas. Further, there is a growing need for the strategies to be integrated. For example, new forms of organizing the health system must include research components to evaluate results of the changes; and fundamental research leading to new life-saving techniques must be accompanied by adjustments in personnel training and financing systems so that the techniques are used appropriately.

The Panel's advocacy of research is based on [illegible] major perspectives: an appreciation of the demonstrated contributions of research to improving health, and a simultaneous recognition of how much remains to be understood—about the basic processes of life, health and disease, human behavior, and social organization.

Without question, the record of research in helping to alleviate human illness and suffering is remarkable. Mothers and children as a group have benefited enormously from such advances as new techniques of prenatal diagnosis, newborn screening, and neonatal therapy that can ease the burden of some genetic and congenital disorders; the development of immunizations for a variety of viral and other infectious diseases; and deepened understanding of reproductive biology leading to the development of contraceptives and improved treatment of infertility, both of which increase the possibility of voluntary fertility regulation. Mothers and children have also shared in benefits enjoyed by the full population from such advances as:

- The development of antibiotics and other drugs for the control or cure of many bacterial and parasitic diseases
- Improvements in surgery and anesthesiology that now permit effective surgical treatment of a wide range of disorders such as congenital anomalies, many forms of neoplastic growth, valvular heart disease, and skeletal disorders
- The ability to eliminate many gross nutritional deficiency diseases
- The development of effective noninvasive diagnostic procedures such as ultrasound imaging and radionuclide techniques

Research in recent decades has also increased our awareness of the potent influence that social, behavioral, and environmental factors exert on human health—information which in turn has influenced various institutions and practices. For example, as knowledge has grown regarding the deleterious effects of certain chemicals and compounds on health, there has been an increase in regulatory activity to limit or eliminate the use of many substances in agriculture, industry, and other sectors. On a different level, our increased understanding of the importance of parent-infant bonding has been reflected in gradual changes in hospital maternity practices to allow newborn infants and their parents to spend more time together in the critical period after birth.

Our appreciation of such advances and their influence on health promotion and disease prevention is matched, however, by an equally powerful recognition of how much remains to be learned. The extent of our ignorance is both sobering and constantly evident. For every example of a useful and exciting research advance, we can cite another unknown. We applaud the development of the vaccine that prevents polio, but search for techniques to prevent muscular dystrophy, cystic fibrosis, and other handicapping conditions; we recognize the enormous contribution of certain recently developed drugs to the treatment of mental illness, but need increased understanding of a range of remaining problems such as autism; we celebrate advances in our ability to detect increasing numbers of inborn errors of metabolism, but realize that we still know how to treat only a few effectively; we know how to screen for and treat a variety of vision and hearing defects, but still search for better ways to manage many learning disorders. Moreover, it is not only our knowledge about various pathological states that is inadequate; so also is our understanding of many basic patterns and processes of normal growth and development, which are particularly central to understanding the full range of health and disease states in infants and children.

THE RESEARCH BASE FOR PROMOTING HEALTH

As it has been used by the Panel, the term research is defined broadly to reflect our evolving understanding of the multiple determinants of human health and disease. Since the late 19th century, the core biomedical disciplines such as physiology and biochemistry have been among the major avenues toward discoveries that improve the health of the population. Progress in this realm of science has been quite extraordinary and the need for continued advances remains pressing.

Recent decades have seen the development of an increasingly sophisticated understanding of the many factors related to health and disease, and of a changing profile of the burden of illness—as illustrated by the prominent position occupied by such problems as accidents, mental illness, and chronic diseases—which is enormously challenging to our ability to achieve effective disease prevention and treatment. Individual behavior is now recognized more widely than ever as an important determinant of health. An illustration of this point from the domain of maternal and child health is our growing recognition of the harmful effects on fetal growth and development of maternal smoking and alcohol consumption. There is also increasing appreciation of the impact on health of changes in the physical and chemical characteristics of the human environment. The effects of these factors and changes are profound, some are probably as yet unrecognized, and most of the long-term consequences are poorly understood, particularly for children, who are so vulnerable to their environments both biologically and emotionally. Finally, we have come to realize with new clarity that the organization of health care services—their cost, accessibility, continuity, and efficiency—exerts a major influence on health status. Health care services mean little if they do not reach those who need them, or are not organized or delivered appropriately.

This broadened perspective has far-reaching consequences for research. It means, among other things, that a wide array of scientific disciplines, pursued at both the fundamental and applied levels, must be employed in our efforts to improve health—biomedical, behavioral, and social research, the population-based health sciences, health services research, and related disciplines. We now recognize, for example, that it is not enough to conduct research leading to the production of a new vaccine. We must also understand how best to organize the health system to ensure that vaccines are distributed appropriately, and why it is that some children do not obtain them despite the proven effectiveness of immunization measures. We not only need biomedical and clinical research to increase our understanding of human reproduction; we also need to know more about the psychological and social factors that influence the reproductive behavior of individuals and couples such as whether contraceptives will be used effectively. We need to continue to develop new ways to define and detect high-risk pregnancies and on a parallel track, to learn why some women do not begin receiving prenatal care until late in pregnancy.

The complexity of many of today's health problems also suggests that multidisciplinary and interdisciplinary investigations are needed, and that multiple approaches to particular problems may well be fruitful. The Stanford Heart Disease Prevention Program, for example, has drawn on a range of knowledge to develop a series of community-based programs designed to lower the risk factors for cardiovascular disease in selected populations. The research project has required a pooling and synthesis of knowledge on such widely divergent topics as cardiovascular risk factors, the uses of the media in conveying health messages, and techniques of group and individual counseling to modify personal health habits (*1*).

Lead poisoning—a significant health risk particularly for urban, low-income children—provides a similar example of the need to pursue multiple paths of research on a problem. Barbara Starfield, M.D. of Johns Hopkins University recently wrote:

> Basic research, operating on the principle that understanding the internal derangements will lead to reductions in the damage from lead poisoning, is directed at elucidating the mechanisms for the occurrence of encephalopathy, anemia and other pathological processes. Clinical research seeks ways of treating and reversing the manifestations of toxicity. As the frequency of plumbism [lead poisoning], particularly in certain locales, became increasingly evident, and as basic research provided a means of detection and effective therapy, screening tests were devised and used in the community. When these community-based studies suggested that hyperactivity and other behavioral deviations might be associated with lead toxicity, the loop from basic to clinical to community research was closed as these observations led to laboratory studies to confirm and explain the observations. The results of screening raised new questions, too, as it became apparent that many children without the classical signs of plumbism were found to have levels of lead as high as in those presenting clinically. A combination of basic, clinical and population-based research will be required to understand the significance of these new observations and to sort out the relative contributions of biologic and ecologic factors responsible for them (*2*).

The discussion could be extended at great length. The point is simply that, given our growing understanding of the multiple influences on health, *public and private support should encourage research in all of the health sciences, and in a manner that facilitates integrated approaches drawing on many disciplines to further advance our ability to protect and improve the health of mothers and children.*

THE FEDERAL ROLE IN HEALTH SCIENCES RESEARCH

Numerous agencies within the Federal Government support health-related research. Within the Department of Health and Human Services (DHHS), the great majority of research pertinent to maternal and child health occurs in:

- The National Institutes of Health, primarily the National Institute of Child Health and Human Development (NICHD)
- The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA), which includes the National Institute of Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), and the National Institute on Alcohol Abuse and Alcoholism (NIAAA)
- The Health Care Financing Administration (HCFA)
- The Administration for Children, Youth and Families (ACYF)

- The Centers for Disease Control (CDC)
- The Food and Drug Administration (FDA)
- The Health Services Administration (HSA), particularly the Office of Maternal and Child Health (OMCH)
- The Office of Health Research, Statistics and Technology, which includes the National Center for Health Services Research (NCHSR), the National Center for Health Statistics (NCHS), and the National Center for Health Care Technology (NCHCT)

It is, of course, difficult to define or quantify the full extent of maternal and child health-related research in DHHS as a whole or indeed in many of these individual agencies. Certain programs are clearly oriented to reproductive and child health; for example, virtually all of the research portfolio of NICHD and the OMCH would be so considered, as would specific components of ADAMHA—such as the clinical infant program of NIMH's Mental Health Study Center, research on the fetal alcohol syndrome supported by NIAAA, and various substance abuse studies targeted on adolescents supported by NIDA—and selected research activities within ACYF such as their child abuse and neglect studies. Similarly, CDC epidemiological surveillance systems focused on such issues as family planning, congenital malformations, infant mortality, and abortion are also clearly oriented to maternal and child health. In general, though, it is difficult to separate maternal and child health research from other health research, simply because many investigations are oriented to issues or problems that are not solely relevant to mothers and children or to those components of the health systems that serve this group only. Many issues investigated by the National Cancer Institute, for example, touch a wider population than women and children, and research supported by HCFA is typically on broad issues in the organization and financing of health services generally, and not on health services used exclusively by mothers and children. Thus, the Panel made no attempt to define the full range of maternal and child health-related research within DHHS.

Other departments and agencies also conduct research that has great relevance to protecting and promoting maternal and child health. Examples include the accident prevention research of the Department of Transportation; the safety testing activities of the Consumer Product Safety Commission; the research oriented to the educational needs of handicapped children that is supported by the Department of Education; and the housing design and safety studies of the Department of Housing and Urban Development. And in particular, the Department of Agriculture (USDA) sponsors a wide range of research into maternal and child health issues. For example, the Children's Nutrition Research Center at Baylor College of Medicine in Houston is one of USDA's six human nutrition research centers. It conducts research into nutrient requirements during pregnancy, lactation, and early life; the standards for nutrient intake and nutritional status assessment in infants, children, and pregnant and lactating women; and the role of diet in growth and development. In addition, approximately 100 research projects are currently being conducted in the land grant university system through USDA's cooperative research program. Most of these projects are concerned with nutrition status of infants, children, and mothers or with nutrition education research for mothers and children. Finally, a few maternal and child health projects funded through USDA's competitive grants program are investigating nutrient requirements during gestation, infancy, childhood, and pregnancy; and behavioral issues, such as determining the factors that shape the preschool child's food preferences.

In reviewing this broad constellation of players, *the Panel supports the pluralism of research orientations and agencies currently supported by the Federal Government, and recommends that no one agency be charged with administering all maternal and child health-related research.* Because each of these departments and agencies has a different mission, each will pursue somewhat different issues. The net result, however, is the examination of an enormous array of health issues from multiple perspectives—an approach which is highly compatible with the Panel's advocacy of support for a wide range of health sciences.

Planning and Coordination

With so many agencies involved in maternal and child health-related research, however, research planning on a broad scale becomes essential. Without consistent and careful review of the activities of all these agencies, and of the relationship of current research priorities to the evolving needs of mothers and children, there is a substantial risk of significant gaps on the one hand, or overlap on the other, in the total research effort. Moreover, it is important to ensure that research agencies with broad, multipurpose mandates such as the NCHCT, NCHSR, and the research component of HCFA pay adequate attention to maternal and child health issues. In supporting the general notion of research planning, the Panel agrees with the Institute of Medicine report "DHEW's Research Planning Principles," which stated, "Health research planning, when well performed ... is a valuable mechanism for developing sound and productive national health research policy. Well conceived and executed planning is the Nation's best assurance that there will be optimal allocation of resources for health research and that precious resources will be utilized effectively" (*3*). Given the fact that today there are more needs and opportunities for productive research than there are funds and manpower to pursue them, planning for rational allocation of resources to areas of the greatest need, importance, and promise is imperative.

We also believe that adequate research planning will do much to improve the predictability of research funding. Federal funding of health research has often been erratic as a result of shifting congressional priorities especially. Even outstanding scientists, in many areas of study, have suffered from the disruptions of fluctuating funding. The trend to shorter Federal research funding cycles for centers, programs, and projects enhances the uncertainties and changeable character of research support. Both increased predictability in funding and the possibility of longer term funding would promote sustained attention to health needs. Research, by its very nature, is a long-term process that flourishes in a stable environment. Scientific results, particularly in fundamental science, are obtained at unexpected times and often through unanticipated channels. Our belief in the value of research planning is strengthened by its potential for providing funding stability for maternal and child health research and, indeed, all health research.

The Panel is aware that there have recently been a number of health research planning activities and legislative proposals that are based on this same general appreciation of the need for a more coherent and rational approach to research support in the public sector. For example, in 1978, Secretary Joseph A. Califano, Jr. initiated a comprehensive 5-year research plan for the health-related agencies of the Department (then, the Department of Health, Education, and Welfare); and NICHD has undertaken the development of a 5-year research plan covering a broad spectrum of research issues in the maternal and child health field. This plan, which will be available in early 1981, promises to be most useful and should be carefully examined by appropriate public bodies. Other agencies within DHHS that conduct health research are also engaged in planning activities of various sorts. Recently, proposed legislation has been introduced that would establish a Presidential level health sciences planning body to recommend broad research priorities and funding levels. Though not wishing to take a stand on the relative merits of such a proposal, the Panel recommends that *if such a group is established for purposes of general health sciences planning, the special research needs and opportunities associated with maternal and child health should be given adequate attention. To help ensure such attention, we also recommend that the membership of the planning group include adequate representation from the broad area of maternal and child health.*

Regardless of the fate of these large-scale planning efforts, the Panel also sees a clear need for increased communication and coordination of maternal and child health research within DHHS specifically. Although each agency conducts its own forward planning with varying degrees of attention to maternal and child health depending on the agency's mandate, there is no group charged with broad "oversight" of the department's research in this area. To fill this need, *the Panel recommends that the Assistant Secretary for Health, with the advice and assistance of the National Commission on Maternal and Child Health and in consultation with the other health-research agencies of DHHS be charged by the Congress with specific responsibility for assessing the broad outlines of DHHS research related to maternal and child health in order to: identify major gaps in the department's research efforts on behalf of this population; help coordinate research among the various agencies; and encourage multipurpose research agencies within DHHS to devote an adequate portion of their resources to maternal and child health-related research.*

In so doing, the Assistant Secretary for Health may find it useful to rely on interagency panels already in existence (such as those on adolescent research and development, early childhood research and development, nutrition, smoking and health, birth defects, population research, and other issues); existing groups such as the National Center on Child Abuse and Neglect Information Clearinghouse and similar resource centers; and the data bases and inventories of research activities maintained by various agencies. *The Panel also recommends that the Assistant Secretary for Health give specific consideration to whether a national registry of federally funded research in maternal and child health should be formed to assist Federal agencies as well as individual investigators in periodic reviews of research progress and needs.* Should such a concept be found useful, it would probably be reasonable to arrange for the responsibilities of the Maternal and Child Health Administration (MCHA—proposed in chapter 11) to encompass the development and administration of such a registry.

The Panel would also urge that the Assistant Secretary for Health and the National Commission on Maternal and Child Health take a leadership role in advocating that Congress appropriate adequate funds for maternal and child health-related research throughout the Deparment. We have noted with concern, for example, that funding for NICHD has not kept pace with the increases granted NIH as a whole, nor with certain institutes in particular. Similarly, we have reviewed the steady decline in the research funds available to OMCH—from $6 million in 1974–1975 to $4.8 million in 1980. Similar examples from other agencies of DHHS could be cited. We find such declines distressing and short-sighted at best, given the magnitude of need, the life-long health benefits that stem from a healthy beginning in life, the many opportunities for prevention-oriented research directed to this population, and other perspectives discussed throughout this report.

In highlighting the need for more adequate research funding in maternal and child health, the Panel also *recommends that the Assistant Secretary for Health give specific attention to encouraging cooperation in maternal and child health research between the public and private sectors.* Several foundations in the private sector—such as the Robert Wood Johnson Foundation, the March of Dimes Birth Defects Foundation, the W. T. Grant Foundation, and the Foundation for Child Development—have made major contributions to the health of mothers and children through research and demonstration programs especially. A recent example of good public-private collaboration is the Johnson Foundation program exploring the use of nurse practitioners in schools and ways to improve rural infant care (*4*, *5*). Such collaboration makes possible demonstration programs that might not otherwise be conducted, underscoring the general importance of improved communication between these two sectors in the future.

RESEARCH PRIORITIES

Given the mandate and composition of the Panel, no attempt was made to develop a comprehensive research agenda for improving maternal and child health. In specific chapters of the report, some research needs in particular areas are noted, although in all cases these are illustrative examples and not meant to imply that the Panel has undertaken an exhaustive review of needed research.

The Panel has been impressed by the number of reports developed by other groups detailing research priorities in certain areas (*6–13*). It has become common in recent years for groups to convene over several months, sometimes years, to survey the state of research in a given discipline or with regard to a particular health problem, and develop a compendium of research topics that have been neglected, that seem especially ripe for progress if given adequate attention, or that have become pressing for various reasons. Such reports were consulted by the Panel and, particularly if used as source material for more comprehensive research planning, would be most helpful in identifying the many important topics which merit sustained research of high quality.

Short of listing specific research priorities, however, the Panel does wish to call attention to some research areas of special importance: fundamental research in general, epidemiology, research on prevention, social and behavioral aspects of health, and health policy, evaluation research, and research on environmental risks.

Fundamental Research

The first area of special priority is fundamental research involving the full range of the health sciences. Fundamental research, often without reference to, or motivation by, a specific health problem, has contributed the knowledge needed for major health advances. For example, the Comroe-Dripps analysis (*6*) shows conclusively that more than 40 percent of the crucial and decisive developments that underlie present capabilities in cardiovascular and pulmonary medicine and surgery derive from untargeted, fundamental research in the biomedical sciences. We believe that the seminal role of fundamental research would be similarly illuminated were comparable studies made of other health care interventions. There is widespread agreement that long-term solutions to many of our most significant health problems will require a more detailed knowledge of the origins and mechanisms of disease, and the nature of human behavior and social interaction. For example, it is through fundamental research in the biomedical sciences that we will come to understand what triggers the onset of labor; such knowledge would have far-reaching implications for reducing prematurity and its sequelae. Similarly, there is widespread agreement that fundamental research holds the key to the ultimate prevention of many of the chronic illnesses and handicapping conditions that so many children endure. In the behavioral area, we know little about why some children raised in the most depressing and destructive environments mature into creative, responsible adults—knowledge which might contribute substantially to designing intervention programs for certain high-risk groups.

We call particular attention to fundamental research in the fields of molecular biology, molecular genetics, and immunogenetics. The implications for human health and further improvements in medicine of the current advances in knowledge of DNA–RNA chemistry, the structure and function of human genetic material, and the many other facets of these new fields are monumental. Although the full benefits to be derived from such fundamental science advances cannot be predicted now, they promise to be substantial. Indeed, we are probably at the edge of an era in which many of the most devastating congenital and inherited diseases may be eased or prevented altogether.

The Panel recommends strongly that *support for fundamental research in the health sciences be sustained and increased as opportunities emerge and resources allow, and that special efforts be made to ensure that support for new or neglected areas of research not be provided at the expense of fundamental research.* The Panel recognizes that in recent budget cycles there has been an effort to increase and stabilize support for fundamental research in many agencies. *The Panel urges that current recognition of the essential role of fundamental science in the total national effort to improve health not fade in future years under various budgetary pressures, but instead become a major, enduring component of the Nation's research planning and funding policies.*

Epidemiology

The Panel has noted a serious lack of population-based research, particularly as gathered over time on a wide range of topics. This lack is apparent for both normal and pathological states and seriously limits our ability to understand, let alone remedy, many of the major health burdens shouldered by children and their families. A recent compendium (7) of needed epidemiological research related to maternal and child health, for example, highlighted the need for: longitudinal studies of pediatric antecedents of adult diseases; long-term studies of the postnatal effects of drugs on both animals and humans exposed in utero; causes of morbidity in infants up to the age of 12 months; socioeconomic, ethnic, and geographic differences in morbidity and mortality in mothers and children under various health care delivery systems; longitudinal studies on stability and change in personal characteristics and life patterns of children and youth during the transition from the home environment to school, and the movement into adolescence and through adolescence into adulthood.

Further, the Panel is concerned about how little is known about the long-term impact, with and without treatment, of the most common illnesses in childhood such as upper respiratory infections. Although it is clear that most of these are self-limited in most children, it is becoming increasingly apparent that some children are subject to repeated experiences with such illnesses, with unknown effects on their overall function, growth, development, and subsequent health. The biological and social factors responsible for this vulnerability are as yet unknown.

One of the factors that limits many such important epidemiological investigations is that longitudinal research is both difficult and expensive to conduct. It typically requires a long-term commitment by the investigators, the supervising institution, and the funding source, usually the Federal Government, which limits grant awards to 5 years. In addition, following a cohort of children, for example, in a mobile society over many years is both logistically difficult and expensive. Such factors lead the Panel to *recommend that congressional appropriations to agencies that conduct longitudinal research should reflect the importance, expense, and need for such investigations. Also, to the extent that it is statistically sound, we urge that more feasible and less costly cross-*

sectional designs be used rather than cohort studies to generate information on various measures over time. One example of a creative approach to collecting longitudinal data is the study of child development in Kauai, Hawaii (*14, 15*). Another example is the "followback" surveys of NCHS. Followback surveys are mail surveys to collect additional information for a sample of births or deaths from individuals or providers of care named on the vital record. Natality followback surveys were conducted from 1963 to 1969 and in 1972 (*16*). Currently a natality followback survey is being conducted using a sample of 1980 births with an over sampling of low-birth-weight infants so that this high-risk group may be studied more extensively. Being conducted concurrently with the natality followback survey is a fetal mortality followback survey which is collecting the same information about a sample of fetal deaths of 28 weeks or more gestation. Data from these surveys will be available in 1982. Given the importance of such work, *the Panel recommends that funding be included in the NCHS budget to conduct these followback surveys on a periodic basis, and that consideration be given to expanding the scope of such surveys to follow infants into childhood and adolescence.* Consideration should also be given to following cohorts of children identified in population-based sample surveys (such as the Health Interview Survey and HANES), such as children with certain defined conditions.

Research on Prevention, Social and Behavioral Aspects of Health, and Health Policy

The Panel wishes to call attention to some of the research issues that emerge from the five concerns outlined in chapter 1. Although many of the strategies for easing these concerns involve changes in the organization and financing of care, it is also apparent that significant contributions may be made by research.

With regard to the first concern—that we do not give enough priority to preventive care and health promotion generally, and do not apply widely enough various preventive strategies known to be effective—the Panel suggests that this relative neglect of prevention is also the case in research. It is of course true that much of biomedical research—especially fundamental research—is ultimately directed toward primary prevention, as embodied, for example, in advances in clinical genetics such as screening and prompt treatment for hereditary defects. However, prevention-oriented research, particularly in the behavioral and social sciences, is far down the agenda of national research priorities. For illustration, the following are some questions still to be answered:

- How to design health education strategies to promote health-enhancing behaviors in children and adolescents, and thereby prevent or lessen adult illnesses which may have their antecedents in habits begun in youth
- How to meet the mental health needs of chronically ill and handicapped children in order to prevent additional burdens of mental distress, particularly at such vulnerable stages as early adolescence

- How to increase the awareness in women of reproductive age of the hazards to the developing fetus of various drugs, chemicals, radiation and other environmental assaults, particularly in the first trimester of pregnancy

The second of the Panel's concerns involves the continuing inequities of health status and access to services among various groups. Although progress in easing this concern is not likely to rest heavily on research, the scientific community has an important role to play in studying, for example:

- The relative merits of various provider arrangements in linking underserved groups to needed health services
- Ways to remove cultural barriers and improve the acceptability and delivery of health services to such groups as Native Americans and recent immigrants

The third concern describes the emergence of psychosocial and behavioral problems as a major component of the health needs of children and pregnant women. The research base in this area is in special need of strengthening, particularly with regard to fundamental research on social and behavioral aspects of health and disease. Our knowledge about organic disease—how to diagnose and treat physical problems—is not matched by an equally rich understanding of psychosocial and behavioral influences on health and how to harness these factors for health promotion. The absence of a vigorous science base in this area limits efforts to improve the health of mothers and children in particular, because it is precisely in this realm that so many problems exist and through which so many solutions must be found. The research questions that emerge from this third concern of the Panel are numerous. Many appear in earlier chapters, particularly those which discuss risks in the physical environment, selected issues in nutrition, and understanding the relationship of behavior and health. Other illustrations of topics on which research is needed include:

- The so-called "critical periods" in human development, in order to understand if and when such periods exist, and the relationship of parent-family-child interactions during the critical periods to future development and health status
- Ways to intervene in certain identifiable patterns of drug use and in the movement from use of some illicit drugs to others
- The psychosocial and behavioral determinants and consequences of alcohol use, with special attention to pregnant women in light of the increased understanding of the fetal alcohol syndrome
- Strategies to help both children and their families adhere to various therapeutic regimens, particularly in the presence of handicapping conditions and chronic illness
- The relationship of diet and the ingestion of specific food substances to various patterns of behavior and development

The fourth concern of the Panel centers on the family—that the health system often does not operate in a way that supports and enhances family cohesiveness and strength, and that the demographic changes in the American family are having significant, inadequately recognized effects on maternal and child health especially. Although strategies to ease these problems will rest heavily on changes in values and a new way of thinking about child health in the broader context of family functioning, contributions from the research community are also needed on such issues as:

- The effectiveness of various techniques of parent education, including child birth education
- The effects on child health and development of different modes of child care such as group day care and various babysitting arrangements
- The efficacy of various strategies to help parents manage the stresses of childrearing, particularly in single parent families and families in which both parents work
- Various ways of actively involving parents and children in medical decisionmaking in order to enhance and strengthen parent-child relationships

The Panel's fifth concern is the excessive fragmentation among the service programs and policies in maternal and child health. Health services research has an obvious contribution to make in helping to evaluate the effectiveness of various services in order to avoid unnecessary complexity and duplication. Similarly, health policy research can help to bring more coherence to the plethora of publicly financed programs for mothers and children and to clarify the relationship among local, State, and Federal roles in administering various programs. Examples of policy-oriented research topics pertinent to this general set of issues include:

- Analysis of the eligibility criteria used by the various public programs related to maternal and child health to assist in making such criteria more coherent
- A comprehensive review of the priority given to issues of maternal and child health by the health planning structures at Federal, State, and local levels to help harness the health planning mechanism for the benefit of this population
- An analysis of the structure and modes of operation of the DHHS regional offices in the area of maternal and child health to clarify and improve their capacity to help States administer various federally supported programs effectively and efficiently

Evaluation Research

One aspect of health services research to which the Panel wishes to call special attention is evaluation research. Time and again, we have found the need for improved information and analysis of the many programs and services providing care to mothers and children. Questions which frequently arise are: Does the program reach the population it is designed to serve? Does the program coordinate its activities with providers of similar services? Is the mix of staff the most appropriate for services to be efficient and effective? Is the program having a beneficial impact on the population it is serving?

As a general matter, the Panel believes it is exceedingly unwise for public funds to be expended through service programs without simultaneous evaluation to measure intended effects. For example, we find an advantage of the OMCH research program is its close ties to the service program. The same staff that is intimately involved with the service program helps to define research questions, stimulates research projects on these questions, monitors the funded research, and has the capacity to translate the research findings back to the service world. *As a general rule, the Panel recommends that programs providing or supporting maternal and child health services—from the local to the Federal level—be required to develop an evaluation plan, built in at the outset, to determine whether the program is meeting its established goals and to help in judgments about whether the program's benefits justify the level of effort and funds needed to sustain it.* Further, the results should be made widely available—published in relevant journals, for example, and not confined to discussions between a given program director and contract manager. The notion of building in evaluation plans at the outset, incidentally, is most important. For example, if home visiting programs are expanded as we strongly recommend, an evaluation component should be included in the program from the beginning in order to answer a variety of questions about how best to organize such programs (see chapter 7).

For similar reasons Congress has provided that 1 percent of Public Health Service program funds and 0.5 percent of Social Security Administration program funds be designated for evaluation purposes. It is the Panel's impression, however, that these monies are not always spent with sufficient care. Too often the program managers—at the Federal as well as State and local levels—have little leverage over the planning and monitoring of the evaluation, and little feedback of the results. Also, these evaluation funds are frequently "raided" and used for purposes only loosely connected to the evaluation of the specific program from which the funds emanate. *The Panel therefore recommends that the MCHA, the National Commission on Maternal and Child Health, and/or the Congress as appropriate review the extent to which funds drawn from maternal and child health programs are being used to generate appropriate and useful evaluation data, and take adequate steps to correct any general misuse of evaluation funds if such is found.* In making this recommendation, we realize that a variety of procedural questions associated with organizing and financing evaluation studies merit attention. For example, it is difficult to involve program staff in evaluation studies without introducing bias into the results. Other problems arise in choosing contractors, evaluation topics, and criteria for evaluation; in increasing the comparability among evaluation studies; in the extent to which there is adequate peer review of evaluation designs and products; and in finding the best ways to involve such agencies as NCHSR at various stages in an evaluation study. Such questions, of course, are not unique to evaluation of maternal and child health programs. As a general matter the Panel would urge that these types of issues be given careful consideration by the DHHS leadership in order to ensure that evaluation research of high quality is a major component of all the department's service programs.

We also note a need for more evaluation research—and health services research generally—conducted by or for State maternal and child health programs in order to improve the quality of the services they provide. It is widely recognized that one of the major reasons there has been so little change, so little improvement in the public program delivery system at the State level during the last few decades, when remarkable changes have occurred in many other parts of the health care system, has been the lack of internal critical study at the State level. Such research may be supported by a variety of agencies, especially OMCH at the Federal level. Therefore, *we urge that OMCH earmark an adequate portion of its total research funds for research initiated and conducted by State maternal and child health programs, with the collaboration of health departments and universities as appropriate, and that the results of such research be a part of the program's annual report and be circulated by OMCH to all state Maternal and Child Health agencies.*

In chapters 5 and 9, another aspect of evaluation research is covered and is only cross-referenced here—the need for improved information regarding the effectiveness, efficacy, and cost-benefits of various health services for mothers and children; the circumstances under which various services are best provided and financed; and the effects of various payment practices on how the health care system operates.

We caution, though, that to do such research will in some instances require that we develop new research designs and systems—and indeed a whole new approach to evaluation studies (both directed at clinical problems and at service organization and delivery problems)—that recognize the differences between the standards and conduct of biomedical research especially and research conducted in the more complete environments of patient care and the health care system generally. For example, our measures of outcome will need to be refined and reoriented. The usual measures of mortality and disability are often inadequate for judging the merits of many components of primary care including services oriented to the psychosocial needs of patients, and particularly of various health promotion activities. The measurement of low birth weight, for example, has proved to be more sensitive than infant mortality in measuring the impact of various prenatal and perinatal events. Such examples need to be expanded. *The Panel urges that special priority be given to developing a range of new health outcome measures in order that the value and impact of many of the services which are especially important to children and pregnant women—such as primary care services for non-life-threatening illnesses and psychosocial interventions—may be adequately assessed.*

Research on Environmental Risks

In chapter 2, the Panel discusses a range of environmental risks to mothers and children, including accident prevention issues, safe water needs, and the risks posed to women and children by chemicals, drugs, and other substances in the physical environment. In that chapter we note that the need for research is pressing in these areas—not only to understand the full extent of environmental risks to this vulnerable population, but also to develop effective strategies for reducing such risks. For example, research is needed on exposure and ingestion tolerances for pesticides—including the long-term effects of ingesting low levels of toxic substances over time—in order to calculate levels adequate to protect infants, children, and pregnant women as well as adults of both sexes.

In particular, *the Panel wishes to reemphasize here that young children, pregnant women, and the fetuses they carry are especially vulnerable to the toxic effects of numerous substances both manmade and naturally occurring in our water, air, food, and elsewhere.* Regulatory approaches to minimizing these risks must be grounded firmly in science, which in turn requires adequate support for high quality research on environmental risks. In drug testing, for example, we need further research to establish safety and efficacy standards specific to children and pregnant women. With regard to food, more information is needed on the effects of food composition, food additives, and nutritional imbalances on the developing child. And we also need to know far more about the effects of various workplace hazards on women, especially pregnant women, although we hasten to add that environmental risks to men are of no less importance. The effects of exposure to various substances on male fecundity, for example, is a topic of increasing concern. We note with approval that the National Institute of Occupational Safety and Health (NIOSH) has established a program of research to identify and help eliminate reproductive effects due to workplace hazards. NIOSH is conducting both basic and applied research to identify mutagens, teratogens, and substances associated with sterility or spontaneous abortions; and epidemiological studies are directed toward estimating expected incidence of reproductive outcomes in the population, identifying groups of workers with abnormal reproductive experience, and determining probable causes. More generally, the *Panel recommends that as national research agendas are developed in coming years, the risks of environmental substances to individuals, and especially to children and pregnant women, be studied with great care and that regulation reflect our emerging understanding of such risks.* One particularly fruitful area of investigation that is most promising is the field of ecogenetics which examines the interaction of human genetic makeup and environmental factors in relationship to health and disease. We would urge that this area of science be strengthened.

DATA NEEDS

In the previous sections, we have noted a variety of important research areas. Common to almost all of them, to some degree, is the need for a more adequate pool of statistical data on a variety of maternal and child health issues. Similarly, in our discussions of how to improve the organization of services for this population, we often noted an absence of important and sometimes quite basic information. Virtually all the reports we received that addressed research needs expressed a similar concern. For example, the President's Commission on Mental Health found that the Nation lacks much needed evidence on the distribution and severity of mental, emotional, and learning disorders in children and youth, especially adolescents, and argued for immediate initiation of surveys to fill this gap. Similarly, when the Panel looked into individual maternal and child health problems and service programs, we found a pronounced need for more adequate reporting systems and for increased surveys to collect various sets of data. For example, earlier in the report we recommend the establishment, nationally and within each State or region, of a sophisticated and policy-oriented data base on accidents, injuries, and poisonings, to aid in targeting resources and programs.

However, before addressing some of the most pressing needs for new information, we wish to stress our concern that much of the massive amounts of data already in hand in many agencies is inadequately analyzed and reported. The analytic staffs of these agencies are not large enough to do justice to these data given the continual pressures for the generation of new information. Therefore, *we recommend that new funds be allocated for increased analytic staff as appropriate in agencies that collect significant amounts of health information. We also recommend that new funds and personnel be allocated for the support of centers for research, analysis, and reporting using existing data bases by scholars and analysts in selected universities and private research institutions.* These funds—which would represent only a fraction of the funds required to generate the data in the first place—could be awarded to the centers as long-term funding and awarded to individual scholars on a short-term competitive basis with the stipulation that the research would involve no new data collection but only further analysis and synthesis of existing data sets.

Within existing systems, the Panel notes that the programs of NCHS and related Federal statistical activities collect a great deal of worthwhile information concerning the health status of American children and the use of health care services by children and their families. These data could be more useful if a few relatively simple changes were made in existing procedures. *The Panel recommends that NCHS be encouraged, and provided with the resources, if necessary, to take such steps as:*

- *Tabulating and reporting child health data, whenever possible, by smaller, more analytically useful age categories*
- *Working with the Bureau of the Census to increase the compatibility of the categories they each use in tabulating data identifying children and families of different ethnic groups*
- *Increasing the compatibility in questions and coding procedures among the various data collection programs, thereby increasing the ability to synthesize results from separate surveys*

With regard to the vital statistics system especially, the Panel noted a number of procedures and opportunities that merit careful consideration. Because the time of greatest risk of death or trauma to a child is at or shortly after birth, it is essential that information be available to monitor the health of children during that period. Currently, the only continuous sources of national data are the certificates of live birth and the certificates of death filed in each registration area. NCHS recommends to the States the U.S. Standard Certificates as a model in the development of their own State certificates; although most States have adopted the model certificates, some have not. Further, in developing their certificates, some States choose to omit some items included in the model certificates, particularly birth certificates. Such items which have special relevance for health monitoring and planning include the month of pregnancy that prenatal care began, number of prenatal visits, marital status of the mother, educational attainment of each parent, and date last normal menses began (used for computation of gestation). Although completeness of reporting is very good for most items, there are some items on the birth certificate for which reporting is not complete, for a variety of reasons. For example, in many States, information about the father can be reported only if the mother is married. Congenital anomalies are very poorly reported on birth certificates, although this is due in part to the fact that many anomalies are not discovered until after the birth certificate is completed and filed with the local registrar. When such social, demographic, and medical information is not reported fully and accurately, it impairs the ability of both local and national health professionals to monitor trends in maternal and child health.

Even though Federal leaders recognize these problems in data collection at the State level, the Federal Government can only furnish the States with technical assistance, guidance, and coordination because vital registration is a State-controlled activity. To ease such problems, *the Panel recommends that NCHS be provided with increased funding and personnel to provide technical assistance to the States to increase the quality and comparability of vital statistics across States.*

The Panel has also been impressed with the need for more complete and sophisticated information associated with the perinatal period. For example, information on the causes and correlates of infant deaths is limited because the certificate used to report an infant death, which is the same certificate used for all other deaths, is restricted to demographic characteristics and cause of death. Correlates of infant death, such as birth weight, gestational age, socioeconomic status, mother's prenatal care, and complications of pregnancy and labor, are not reported on the death certificate even though such items generally appear on the birth certificate and on the report of fetal death. (Fetal death generally includes any product of conception not born alive, such as stillbirth or miscarriage, but this does not include induced termination. NCHS recommends data on fetal deaths be collected for fetuses of 20 weeks or more gestation.) Therefore, one relatively straightforward way to obtain pertinent information on perinatal and infant mortality is to link the death records of an infant with the corresponding birth record.

Further, such information drawn from appropriate linkage of infant birth and death certificates should be related to health system variables such as the adequacy of a region's maternal and perinatal services, in order to assess various aspects of the health system in the important perinatal period. Other similar examples of data needs and opportunities in the perinatal period could be presented. Accordingly, *the Panel recommends that MCHA, NCHS, and other appropriate institutions review the adequacy of, and take steps to improve as needed, current systems for collecting important information in the perinatal period. Specific attention should be given to (1) establishing a perinatal surveil-*

lance system in each state to aid in further defining the causes and correlates of infant mortality and morbidity; and (2) increasing the ability of states and NCHS to generate and analyze national data based on linked records of live births and infant deaths. The Panel believes the improved data bases that would result from such activities would do much to help health authorities at all levels of government pinpoint selected health problems in the perinatal period more accurately, and target their resources appropriately.

In addition to these issues in the vital statistics system, the Panel also identified an additional three sets of problems in available data related to maternal and child health. First, we noted that NCHS has in the past collected and reported considerable information about the normal growth and development of American children. Analysis of physical growth patterns using data from the Health Examination Survey and the Health and Nutrition Examination Survey is an example. In recent years, however, resource constraints have forced the NCHS to focus more narrowly on measurements of overt disease and severe disability at the very time when pediatric practice and child health research have been placing a greater emphasis on variability in the development and functioning of children, on incipient disorder and on psychosocial disorders that do not fit easily into the traditional framework of infectious disease and injury. Therefore, we *recommend that NCHS be provided the resources to continue and expand its data collection and analysis concerning the physical, motor, intellectual, social, and emotional development of normal children.* This is particularly important because the health status of young children is poorly defined by existing methods of measuring disability in terms of the limitation or restriction of "usual activity."

Second, we note a serious lack of data on handicapping conditions and an equally significant lack of agreement among parents, teachers, and physicians regarding the identification and labeling of handicapped children. *We recommend, therefore, that NIH, NCHS and other appropriate groups develop functional categories to accompany diagnostic categories for use in surveys to determine the prevalence of handicapping conditions, and then conduct such surveys in order to produce more accurate and complete information about the nature and extent of such conditions in American children.*

Last, through hearings, site visits, and other activities, the Panel heard much about the data reporting burdens that administrators of service programs bear. We also understand well the demands of accountability in expending public funds, and that in some instances, there truly is a need for more data, not less. It is a difficult set of problems at best, and there is no easy answer. But to help ease such problems, *we recommend that MCHA review and assess existing State and Federal recordkeeping and reporting requirements for maternal and child health service programs supported by DHHS and recommend changes in such processes to the Secretary of DHHS and to program administrators, with the goal of consolidating or integrating data collection processes and forms where possible.*

TRAINING ISSUES

A corollary to the Panel's recommendations in the research and data collection areas concerns the adequacy of our national research training efforts. It is the Panel's overall impression that there is a decreasing and inadequate investment of public funds in training scientists in various disciplines needed to advance the health of mothers and children. We support the efforts of the National Academy of Sciences' Committee on a Study of National Needs for Biomedical and Behavioral Research Personnel (*17*) which is examining many aspects of Federal support of research training. *A well-trained, steady supply of researchers is a cornerstone of any national strategy to prevent disease and promote health in the population, including mothers and children. The Panel views the current trends toward erosion of such support in some areas with great concern. We find it shortsighted in the extreme to skimp on training investments, given the probable long-term results of such actions.* For example, training funds available through the principal child health research agency of DHHS, NICHD, have fallen from $14.8 million in 1974 to $9.8 million in 1979. Similar declines have touched other components of NIH and DHHS as well. In addition to the decline in total dollars, inflation has necessitated an increase in stipend amounts given to individual trainees, further decreasing the number of trainees who can be supported.

One distressing manifestation of the decrease in training support is the decline in the amount of clinical investigation being pursued—that form of research which bridges the basic sciences and patient care. For example, largely as a result of the recommendations of the National Diabetes Advisory Board, there has been great interest among funding agencies in supporting research on diabetic mothers and their children. However, there is an insufficient supply of clinical investigators to pursue these topics. More generally, the NICHD notes an overall decline in available manpower to study ways to prevent and treat high-risk pregnancies and to manage high-risk infants. The Panel does not mean to suggest that the decline in the amount of clinical investigation is due solely to erosion in training support. In fact, multiple pressures in addition to training problems are currently burdening the field of clinical investigation. These pressures, increasingly the subject of concern in science policy bodies, include problems in research funding (especially the current emphasis on short funding cycles and the expectation of quick results), in academic career paths, and a host of others. But the decline in public support of clinical investigation trainees is surely a major barrier and one the Panel urges be eased.

One additional aspect of the training issue should be noted. The settings and sites in which the training of health researchers occurs has an obvious influence on the interests and topics subsequently pursued by such scientists. At present, it is our impression that the number of research training opportunities is relatively scarce in primary care and other settings where many health promotion and disease prevention services are delivered. In order to further stimulate research on the types of health issues and interventions which are in the domain of primary care—and which are particularly important to maternal and child health—*the Panel recommends that research training opportunities be increased in ambulatory primary care settings and other settings oriented to health promotion and disease prevention.*

There are, of course, other issues in research policy which, like training support, are pertinent to maternal and child health but certainly go well beyond this population. We recognize the importance, for example, of such issues as research information retrieval and dissemination, and problems in balancing applied versus fundamental research. We have chosen, however, not to address ourselves to them in this report—not because the topics are unimportant (indeed, in the aggregate they are of tremendous concern)—but more because their elucidation and amelioration are questions of national science policy generally and fall outside of the Panel's expertise and mandate.

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APPENDIXES

APPENDIX A

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APPENDIX B

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APPENDIX C

BACKGROUND PAPERS PREPARED FOR THE SELECT PANEL

I. *Health Protection and Promotion*

Environmental Hazards to Children: Assessment and Options for Amelioration; Leon S. Robertson, Ph.D.

Nutrition Education and Information; Johanna Dwyer, D.Sc.

Nutritional Program Options for Maternal and Child Health: A Summary; Barry M. Popkin, Ph.D., John Akin, Ph.D., Mildred Kaufman, and Maurice MacDonald, Ph.D.

Behavioral Aspects of Maternal and Child Health: Natural Influences and Educational Intervention; Patricia Dolan Mullen, Dr. P.H.

II. *Needed Services*

Background Notes on Various Approaches to Determining Health Services Needed by Infants and Children, Adolescents, and Pregnant Women; Lisbeth B. Schorr and Robert J. Haggerty, M.D.

A Child's Beginning; Samuel S. Kessel, M.D., Judith P. Rooks, C.N.M., and Irvin M. Cushner, M.D.

The Health Needs of Infants and Children Under 12; Susan S. Aronson, M.D.

Adolescents: Health Status and Needed Services; Lorraine V. Klerman, Dr. P.H.

Health Care for Chronically Disabled Children and Their Families; Henry T. Ireys, Ph.D.

III. *Access to Care*

Children's Health Care: The Myth of Equal Access; Diana Dutton, Ph.D.

The Organization of Primary Health and Health-Related Preventive, Psychosocial, and Support Services for Children and Pregnant Women; Bonnie Lefkowitz, and Dennis Andrulis, Ph.D.

IV. *Financing and Organization of Services*

Improving the Financing of Health Care for Children and Pregnant Women; Stanley B. Jones

The Organization and Financing of Child Health Services: Options for Policy; Anne-Marie Foltz, Ph.D.

The Special Health-Mental Health Needs of Children; Larry B. Silver, M.D.

V. *Planning and Administration*

Title V—The Maternal and Child Health and Crippled Children's Services Section of the Social Security Act: Problems and Opportunities; Lorraine V. Klerman, Dr. P.H.

The Effective Integration of Maternal and Child Health Concerns into the Generic Health Systems Planning Process; Mary Ann Holohean

Federal and Administrative Arrangements for Maternal and Child Health; Karl D. Yordy

VI. *Health Manpower*

Child Health Professionals: Supply, Training, and Practice; Peter Budetti, M.D., J.D., Peggy McManus, Suzanne Stenmark, and Lauren LeRoy

New Health Professionals in Child and Maternal Health; Gloria Ruby

Background Paper on Nursing; Katherine B. Nuckolls, R.N., Ph.D.

VII. *Research and Information Needs*

Reflections on Maternal and Child Health Programs: Reviewing the Literature: 1975-80; George Silver, M.D., with the assistance of Raymond Borsori

National Information Needs in Maternal and Child Health; Nicholas Zill, Ph.D., and Robin Mount

VIII. *Select Panel for the Promotion of Child Health Workshop on Organization of Health Services*

Summary and Themes of Workshop; prepared by Vicki Weisfeld

Copies of the background papers are available for sale through:

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Stock Number 017-002-00141-1

Volume III, A Statistical Analysis
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APPENDIX D

DISSENTING VIEWS

Chapter 9: Financing Health Services

The Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services dissents from the recommendation that *if a universal national health plan cannot be put in place relatively soon, the Panel urges enactment of national health insurance for children and pregnant women.* While recognizing the benefits of universal coverage, the Assistant Secretary notes that the Carter Administration has generally favored a policy of "neediest first," when it comes to phasing in a national health plan. This translates into extension of coverage to very poor adults with no existing source of payment whatever for health care before any extension of coverage to better-off children.

The Assistant Secretary for Planning and Evaluation also dissents from the recommendation that *all services defined by the Panel as "needed" should over the long run be covered in full, without cost sharing by the patient or family.* Cost sharing for nonpoor families can be structured so as not to interfere with needed access, and to encourage preventive and primary care as opposed to high-technology inpatient care, while helping to minimize program costs.

Chapter 11: Federal Administrative Arrangements

The Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services dissents from the Panel's recommendation that *the DHHS Secretary establish a Maternal and Child Health Administration (MCHA) as an agency of the Public Health Service.* The Assistant Secretary has doubts about the effectiveness of this type of reorganization in achieving appropriate emphasis on child health goals, and questions especially the separation of child health from other health service delivery programs in the Public Health Service's Health Services Administration and Bureau of Community Health Services.

APPENDIX E

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APPENDIX F

GLOSSARY: ABBREVIATIONS FOR ORGANIZATIONS AND AGENCIES

ACYF	Administration for Children, Youth and Families
AFDC	Aid to Families with Dependent Children
ADAMHA	Alcohol, Drug Abuse, and Mental Health Administration
AAFP	American Academy of Family Practice
AAP	American Academy of Pediatrics
ACOG	American College of Obstetricians and Gynecologists
AMA	American Medical Association
ANA	American Nurses' Association
BCHS	Bureau of Community Health Services
BMCHS	Bureau of Maternal and Child Health Services
CDC	Centers for Disease Control
CHAP	Child Health Assurance Program
C&Y	Children and Youth project
CHAMPUS	Civilian Health and Medical Program of the Uniformed Services
CETA	Comprehensive Employment and Training Act
CSFP	Commodity Supplemental Food Program
CHC	Community Health Center
CMHC	Community Mental Health Center
DHHS	Department of Health and Human Services
(D)HEW	Department of Health, Education, and Welfare
EPSDT	Early and Periodic Screening, Diagnosis and Treatment
ESEA	Title I—Elementary and Secondary Education Act
ER	Emergency room
EPA	Environmental Protection Agency
EFNEP	Expanded Food and Nutrition Education Program
FCC	Federal Communications Commission
FDA	Food and Drug Administration
GAO	U.S. General Accounting Office
HCFA	Health Care Financing Administration
HMO	Health Maintenance Organization
HSA	Health Systems Agency
ICHP	Improved Child Health project

IPO	Improved Pregnancy Outcome Program
IHS	Indian Health Service
IOM	Institute of Medicine, National Academy of Sciences
MCH	Maternal and child health
MCHA	Maternal and Child Health Administration
MIC	Maternity and Infant Care project
NCHCT	National Center for Health Care Technology
NCHSR	National Center for Health Services Research
NCHS	National Center for Health Statistics
NHSC	National Health Service Corps
NHTSA	National Highway Traffic Safety Administration
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NICHD	National Institute of Child Health and Human Development
NIDA	National Institute on Drug Abuse
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NIOSH	National Institute of Occupational Safety and Health
NMA	National Medical Association
NHC	Neighborhood Health Center
NET	Nutrition Education and Training
OAPP	Office of Adolescent Pregnancy Programs
OHDS	Office of Human Development Services
OTA	Office of Technology Assessment
OPD	Outpatient department
PSRO	Professional Standards Review Organization
PUFF	Proposed Use of Federal Funds
PHS	Public Health Service
P.L. 93–641	National Health Planning and Development Act
P.L. 94–142	Education for All Handicapped Children Act
P.L. 95–626	Health Services and Centers Amendments of 1978
RHC	Rural Health Clinic
SHCC	State Health Coordinating Council
SHPDA	State Health Planning and Development Agencies
Title V	Maternal and Child Health, Social Security Act
Title X	Family Planning, Public Health Service Act
Title XIX	Medicaid, Social Security Act
Title XX	Social Services, Social Security Act
USDA	Department of Agriculture
WIC	Supplemental Food Program for Women, Infants and Children

APPENDIX G

LEGISLATIVE MANDATE

Reprinted from Public Law 95–626, November 10, 1978.

Establishment. 42 USC 289d note.

Sec. 211. (a) The Secretary of Health, Education, and Welfare (hereinafter in this section referred to as the "Secretary") shall establish within the Office of the Secretary a Select Panel for the Promotion of Child Health (hereinafter in this section referred to as the "panel").

(b) (1) The panel, after reviewing all the significant medical, scientific, behavioral, and epidemiological studies concerning the promotion of child health and the prevention of childhood diseases and concerning the efficacy and efficiency of child health programs, shall—

(A) formulate specific goals with respect to the promotion of the health status of children and expectant mothers in the United States;

(B) develop a comprehensive national plan for achieving these goals and otherwise promoting the health of children in the United States; and

Report to Secretary and congressional committees.

(C) transmit to the Secretary, to the Committee on Interstate and Foreign Commerce of the House of Representatives, and to the Committee on Human Resources of the Senate, not later than eighteen months after the date of the enactment of this Act, a report detailing the comprehensive national plan it has developed and recommendations for such adminsitrative, legislative, and other actions as it deems appropriate to implement this plan and to otherwise promote the health of children in the United States.

National plan.

(2) The panel shall include in its comprehensive national plan (developed under paragraph (1)(B)) recommendations with respect to—

(A) the appropriate type and quantity of preventive health care and other health services needed by children in general and by particular types of children at risk;

(B) the appropriate methods (and providers) for delivering and financing the delivery of such services;

(C) the appropriate methods for coordinating and consolidating, within an agency and between agencies, the administration of child health promotion programs;

(D) the need for research into the delivery of such services and the promotion of child health;

(E) the appropriate methods for instructing children and parents in methods of maintaining their health;

(F) the encouragement of innovative programs to promote child health;

(G) the appropriate methods (including demonstration programs) for applying research findings to delivery of health services to children and otherwise to promoting the health of children;

(H) the appropriate relationship between child health promotion programs and health planning organizations;

(I) the appropriate support of training of health personnel for child health promotion programs; and

(J) the appropriate technical assistance to States to implement child health promotion programs.

Membership.

(c)(1) The panel shall be composed of the Assistant Secretary for Health and the Assistant Secretary for Planning and Evaluation, who shall serve as ex officio members, and of fifteen other members who shall be appointed by the Secretary not later than sixty days after the date of the enactment of this Act. Among members of the panel appointed by the Secretary, the Secretary shall appoint not less than three, nor more than five, individuals employed by the Department of Health, Education, and Welfare, and shall appoint representatives from the scientific, medical, dental, allied health, mental health, preventive health, public health, and education professions, as well as consumers and representatives from State and local health agencies.

(2) The Secretary shall designate, at the time of appointment of members of the panel, one member to serve as chairperson and another to serve as vice chairperson of the panel.

Term of office.

(3) Members of the panel shall serve for the life of the panel and the Secretary shall appoint individuals to fill vacancies on the panel as they may arise.

Compensation.

(4) Each member of the panel (who is not a full-time officer or employee of the United States) shall be entitled to receive the daily equivalent of the annual rate of basic pay in effect for grade GS-18 of the General Schedule for each day (including traveltime) during which the member is engaged in the actual performance of duties vested in the panel. All the members of the panel shall be allowed, while away from their homes or regular places of business in the performance of service for the panel, travel expenses (including per diem in lieu of subsistence) in the same manner as persons employed intermittently in the Government service are allowed expenses under section 5703 of title 5, United States Code.

(d)(1) Upon the request of the panel, the head of any Federal agency is authorized to detail, on a reimbursable basis, any of the personnel of such agency to the panel to assist the panel in carrying out its functions.

(2) The Secretary shall provide the panel with such administrative services and facilities as may be required to carry out its functions.

(e)(1) The panel may, for purposes of carrying out its functions, hold such hearings, sit and act at such times and places, take such testimony, receive such evidence, and appoint such advisory committees as it may deem advisable.

(2) The panel may secure directly from any department or agency of the United States information necessary to carry out its functions. Upon request of the chairperson of the panel, the head of each such department or agency shall, to the extent permitted by law, furnish the information and otherwise cooperate with the panel.

(f) The panel shall cease to exist ninety days after the date of submittal of the report described in subsection (b)(1)(C).

Appropriation authorization.

(g) There is authorized to be appropriated $1,000,000 for the fiscal year ending September 30, 1979, to carry out this section. Sums appropriated under this subsection shall remain available for expenditure until the date the panel ceases to exist.

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